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April-May 2026

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Breakthrough Infections

What to Know and Do

Preparing the Essentials of an Emergency Toolkit

Three Cs of Caregiving for Chronic Illness

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Diagnosing and Treating Good's Syndrome

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If you are experiencing recurrent infections despite being on standard IgRT, ask your doctor if ASCENIV may be right for you.

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Important Safety Information for ASCENIV™

WARNING: RISK OF BLOOD CLOTS (THROMBOSIS), POOR KIDNEY FUNCTION, AND INABILITY TO FILTER WASTE FROM KIDNEYS. BLOOD CLOTS MAY OCCUR WITH INTRAVENOUS IMMUNE GLOBULIN PRODUCTS, INCLUDING ASCENIV.

Before taking ASCENIV, talk to your doctor if you:

- Are of advanced age
- Are unusually sedentary (long periods of sitting down or inactive)
- Are taking estrogen-containing medicines (birth control pills, hormone replacement therapy)
- Have a permanent intravenous (IV) catheter
- Have hyperviscosity of the blood (diseases such as multiple myeloma or other causes of elevated proteins in the blood)
- Have cardiovascular (heart) problems or previous history of stroke

Thrombosis may occur even if you do not have any risk factors.

Serious kidney problems and death can also happen in certain patients who receive such products.

If you are at high risk of thrombosis or kidney problems, your doctor should adjust the dose of ASCENIV and will monitor you for signs and symptoms of thrombosis and viscosity, as well as kidney function.

What is ASCENIV (immune globulin intravenous, human-slra)?

ASCENIV (immune globulin intravenous, human-slra) is a prescription medicine to help adults and adolescents (12 to 17 years old) with primary immunodeficiency fight and prevent infections. ASCENIV is for intravenous administration only. ASCENIV is made from healthy human blood/plasma.

Who should not use ASCENIV?

ASCENIV should not be used if you had a severe allergic reaction to human immune globulin or if you have been told by a doctor that you are immunoglobulin A (IgA)-deficient and have developed antibodies to IgA and hypersensitivity after exposure to a previous plasma product.

What are possible warnings and precautions with taking ASCENIV™?

Hypersensitivity. Severe allergic reactions may occur with immune globulin products, including ASCENIV. If you have a severe allergic reaction, stop the infusion immediately and get medical attention. ASCENIV contains IgA. If you have known antibodies to IgA, you may have a greater risk of developing potentially severe allergic reactions.

If you take ASCENIV or a similar immune globulin product, you could experience a serious and life-threatening blood clot (thromboembolism). This may include pain and/or swelling of an arm or leg with warmth over the affected area, discoloration of an arm or leg, unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, numbness, or weakness on one side of the body. If you are at risk, your doctor may decide to adjust the dose of ASCENIV. Your doctor will monitor you for any signs or symptoms of blood clots or poor blood flow in your arteries.

Always tell your doctor immediately if your medical history is similar to what is described here, and especially if you experience any of these symptoms while taking ASCENIV.

Kidney problems or failure. Kidney problems, kidney failure, and death may occur with use of human immune globulin products, especially those containing sucrose (sugar). ASCENIV does not contain sucrose.

If you have kidney disease or diseases with kidney involvement, your doctor should perform a blood test to assess your hydration level and kidney function before beginning immune globulin treatment and at appropriate intervals thereafter. If your doctor determines that kidney function is worsening, they may discontinue treatment. If your doctor determines you to be at risk, they may start your dose of ASCENIV at a safe level.

People taking human immune globulin products, including ASCENIV, may experience hyperproteinemia (high levels of protein in the blood), hyponatremia (low levels of sodium in the blood), and hyperviscosity (poor blood flow). Your doctor may perform certain blood tests and monitor you to minimize any of the above risks.

Aseptic meningitis syndrome (AMS). Aseptic meningitis is a non-infectious inflammation of the membranes that cover the brain. It causes a severe headache, which may occur with human immune globulin treatment, including ASCENIV. AMS usually happens within a few hours to 2 days after treatment. AMS is more commonly associated with higher doses of treatment and/or after rapid infusion. Your doctor may perform a neurological exam, including spinal tap (sampling fluid which surrounds the spinal cord) to evaluate your condition and to rule out other causes of meningitis.

Hemolysis. Hemolysis refers to the destruction of red blood cells. Immune globulin products, including ASCENIV, may contain certain antibodies that can result in the rupturing of red blood cells. Your doctor should monitor you for signs and symptoms of hemolysis, which may include additional confirmation tests.

Taking intravenous human immune globulin products may cause a build up of fluid in the lungs (pulmonary edema) that is unrelated to heart problems. Your doctor should monitor you for lung-related side effects and may conduct appropriate tests that can detect the presence of certain white blood cells (anti-neutrophil antibodies) in the drug or your blood. If needed, your doctor may decide to use oxygen or other respiratory methods to help your breathing.

Transmissible infectious agents. Because ASCENIV™ is made from human blood, it may carry a risk of transmitting infectious agents such as viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent, and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent. Your doctor will report to the manufacturer any cases of suspected infections spread by the product.

Interference with lab tests. Because ASCENIV contains a variety of antibodies that are infused into your body, blood tests to determine antibody levels may provide misleading interpretations. Be sure to always tell your doctor, nurse, or lab technician of any medicines you are taking and that you are using ASCENIV.

Interactions with medicines. ASCENIV can make vaccines (like measles, mumps, rubella, and chicken pox vaccines) less effective in your body. Before you get any vaccines, tell your healthcare provider that you take ASCENIV.

What are other possible side effects of ASCENIV?

In clinical studies of ASCENIV, some patients experienced the following:

- Headache
- Sinus inflammation (sinusitis)
- Diarrhea
- Intestinal lining inflammation caused by virus (gastroenteritis)
- Common cold (nasopharyngitis)
- Upper respiratory tract infection
- Bronchitis
- Nausea

These are not all the possible side effects of ASCENIV. Talk to your healthcare provider about any side effect that bothers you or that does not go away.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

Visit asceniv.com for Full Prescribing Information for ASCENIV.

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April-May 2026 | Contents

Features

Up Front

Departments

Columns

Sources

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About IG Living
IG Living magazine brings together patients, advocates and caregivers in the immune globulin (IG) community.

IG Living, (ISSN 1949-4548), published bimonthly, is a community service provided by FFF Enterprises, 44000 Winchester Road, Temecula, CA 92590, (800) 843-7477 x1362, fax (951) 699-9655.

Subscriptions to IG Living are free, and readers may subscribe at IGLiving.com or by calling (800) 843-7477 x1461.

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Care Strategies for Optimal Well-Being

Care strategies for chronic illness are essential for optimal well-being because they provide structure, consistency and early intervention in conditions that do not resolve on their own. Effective care strategies also support mental and emotional health by reducing uncertainty, preserving independence and empowering patients and caregivers to respond confidently to changes.

Care strategies are especially important for breakthrough infections. When receiving immune globulin (IG) therapy, you will experience milder or less frequent infections, but you still remain at risk for breakthrough infections. Why? Antibody levels fluctuate between doses and may not be high enough at all times to prevent exposure from leading to infection. In addition, IG does not protect equally against all viruses and bacteria, particularly newer or rapidly mutating pathogens. We explain this in our article "Breakthrough Infections: What They Mean and How to Treat Them" (p.24), as well as discuss treatment strategies such as increasing IG doses and prescribing prophylactic and on-demand antibiotics and early antiviral medications. Importantly, we explain why self-care and care coordination among specialists is crucial.

Another care strategy is an emergency toolkit. Having medications, medical summaries, emergency contacts, symptom action plans and supplies ready can reduce delays in care, prevent complications and lower stress during critical moments. In our article "Your Emergency Toolkit: Being Prepared with a Chronic Condition" (p.28), we list the most important items you should include in your toolkit such as a medical ID, a personal health summary, adequate medication supplies, a list of medications and prescribers, a go-bag for when you need to leave the home quickly, as well as items that can help manage your emotional and mental health.

Caregivers also function as a care strategy because their actions directly influence a patient's health outcomes, safety and quality of life. They act as care coordinators and advocates, and they provide emotional stability and reduce stress — all of which is an essential, ongoing therapeutic intervention itself. We provide tips for our caregiving readers in our article "Caregiving for Chronic Illness: Practical Strategies for Comfort, Compassion and Companionship" (p.36). Specifically, we cover the three Cs of caregiving — comfort, compassion and companionship — to help create a framework that helps patients and caregivers not merely cope, but live. We also provide three tables that list helpful strategies for each of the three Cs.

As always, we hope you enjoy these articles, as well as the many more educational and insightful topics presented in this issue of *IG Living*.

Ronale Tucker Rhodes

Ronale Tucker Rhodes, MS

IGLiving

Our mission is to support the
IG community through education,
communication and advocacy

A community service from
FFF Enterprises, Inc.

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  - *IG Living, a magazine dedicated to the IG community*

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When Pulling Back Feels Easier

By Abbie Cornett, MBA

WITH EVERYTHING going on in the world right now, it's easy to pull back. I know I have. I used to wake up every morning, pour my coffee and read the news. Lately, I don't do that anymore. Instead, I ask my husband, "Is there anything I actually need to know?" Then I do the crossword and sudoku, drink my coffee and avoid the rest. While this may seem like I am burying my head in the sand, it allows me to start the day less anxious, but it also leaves me feeling disconnected.

What I didn't expect was how much that disconnection would bleed into other parts of my life. I've noticed myself turning down social plans more often. I've been taking longer to respond to texts. I've gone quiet with people I care about, not because I don't want to talk to them, but because everything just feels like too much. Avoiding what feels overwhelming sounds like it should help, but for me, it hasn't. Instead, my world has started to feel smaller.

For many people living with chronic illness, this kind of isolation is familiar. Illness has a way of slowly shrinking your days without you even realizing it. So much time and energy goes into just managing health. Appointments, treatments, lab work, medications, insurance calls, prior authorizations, denials, appeals — it all adds up. By the time that's done, there isn't much left. Even short conversations can feel exhausting. Sometimes rest feels like the only thing you have the energy for, and social connections quietly fall away.

After diagnosis, a lot of people grieve the life they thought they would have. Both plans and expectations change, and along with that comes a sense of loss that isn't discussed. Pulling away from friends and family often isn't intentional. It can come from feeling embarrassed about canceling plans again or from being tired of explaining why you're sick when you "don't look sick." Over time, it can become easier to stop explaining altogether. That kind of isolation isn't a choice; it's a coping mechanism. But when it goes on for too long, it can take a real toll on your mental health.

Staying connected doesn't mean forcing yourself to do something you don't have the energy for. Connection can be small. It can be a quick check-in with a friend, family member or co-worker. Sometimes, it's being part of an online group where you can read along without feeling any pressure to respond. Other times, it's simply being honest about your limits, rather than pushing through and paying for it later.

There is something powerful about connecting with people who already understand chronic illness. When you don't have to explain or justify how you feel, the conversation changes. Shared experience brings comfort. It reminds people they aren't imagining things and aren't alone.

Social media can be part of keeping connected. When leaving the house isn't realistic, social media allows you to engage on your own time and can make a real difference. Sometimes just reading someone else's post and thinking, "Yes, that's exactly how I feel," is enough to remind you that you belong somewhere.

And if you find yourself really overwhelmed or stuck in that fog of isolation, it's OK to ask for professional help. Talking with a therapist or counselor doesn't mean you're weak; it means you're taking care of yourself. A therapist gives you a safe space to talk about what's going on and helps you understand your feelings in a way you might not be able to on your own. Many people feel less lonely and stressed after receiving this kind of support, and it can provide you with tools to cope with challenging days and reconnect with others. Reaching out for help can be one of the strongest things you do for yourself. Asking for support is not a failure. Staying connected, even in small ways, is part of taking care of yourself. Community doesn't have to be loud or constant. It can be quiet, flexible and built slowly.

Noticing that you're starting to feel isolated is the first step in reconnecting. While reaching out can feel uncomfortable, it matters for your mental and emotional health. Remember, reconnecting doesn't have to happen all at once. Small steps are enough. Sometimes that means calling a friend, saying yes to a coffee date or choosing to engage with someone on social media instead of scrolling past. Those moments may seem small, but they can remind us that we're still connected and still part of something bigger. IG

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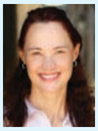

ABBIE CORNETT, MBA, is the patient advocate for *IG Living* magazine. She can be reached at patientadvocate@igliving.com or (800) 843-7477 x1366.

What's a Boundary You've Learned to Set?

1) Asking for accommodation as needed without feeling guilty or apologetic or going into long explanations; 2) Refusing to engage with unsolicited medical advice. Online, I completely ignore those comments; in person, I just say 'uh-huh' and do not respond more to it; 3) Learning to say "I can't make it" or "I have other plans" or "no" without launching into long excuses or explanations; 4) Insisting on specific things for medical care for my own self protection, like not allowing nurses to raise my intravenous immune globulin rate above what the doctor's orders say.

A boundary I set for myself is listening to my body saying enough done for today.

A boundary I finally set for myself: Do not worry about things that are out of my control. I don't have the energy to waste on things I can't control. What can I control? Me. And how I react to what's happening to me.

Distancing myself from toxic people who create unnecessary drama. It's good for my mental and physical health.

My infusion runs over two days. I don't entertain or have visitors until after my infusion and I have had one or two recovery days. Most people understand; however, some do not.

I always request that my healthcare providers wear a mask.

What's One Thing Only Someone with a Chronic Illness Would Understand?

Carrying a list of medications, drug allergies, surgeries, conditions and doctor information everywhere you go.

Constantly planning/anticipating for the "just in case" moments/situations when you go out.

That you can "look good" and still be sick and in pain! Before my disability hearing before a judge (fourth review after three denials), my attorney advised me to stay up all night before the hearing, wear no makeup, wear nice but not good clothes and take all assistance devices with me (cane and brace in my case). Judge approved my case in five minutes!

Perfection in imperfection and that people do things for lots of reasons unspoken (all around), so it's never as it appears.

Why plans are cancelled last minute.

Join the conversation! Connect with other immune globulin patients through IG Living's Facebook page at www.facebook.com/IGLivingMagazine. Each day, we post interesting articles and facts, as well as thought-provoking questions you can weigh in on. These are some snapshots of what's being discussed.

Can Switching from SCIG Vials to Prefilled Syringes Affect Blood Work?

I have been diagnosed with common variable immune deficiency (CVID) and have been on subcutaneous immune globulin (IG) therapy at a stable dose for some time. Recently, my infusion method was changed from vials to prefilled syringes. Since this change, some of my recent blood work has shown results that are outside of the normal range, including indicators related to anemia and immune cell counts. This has raised concerns for me, as I have been feeling unwell and am worried that my levels may be trending lower.

Because there is no immunologist in my local area, my care is currently being managed by a hematologist. I have been told that my levels are acceptable, but I remain concerned and would like additional input. Specifically: Could switching from vials to prefilled syringes affect absorption, dosing accuracy or blood levels? Are the abnormal lab trends something that should be monitored more closely in someone with CVID on IG therapy? Would additional testing or dose adjustment be appropriate? Given that I do not have access to a local immunologist, what are the best options for finding one (such as telemedicine, academic medical centers or national referral programs)?

I am looking for guidance to understand my lab results better, ensure my treatment is appropriate and find specialized care for my condition.

Abbie: I reached out to Terry O. Harville, MD, PhD, medical director of the Special Immunology Laboratory at the University of Arkansas for Medical Sciences, and Leslie Vaughan, RPh, CSP, IgCN, chief operations officer for Nufactor, a specialty infusion company, and they said switching from SCIG vials to prefilled syringes should not cause changes in blood levels. The medication itself is the same product; the only difference is the delivery method. There is no evidence that absorption, dosing or effectiveness changes simply because the product is administered from a prefilled syringe rather than a vial.

Abnormal blood counts, however, should not be dismissed without further evaluation. Without reviewing the full laboratory results and trends over time, it is not possible to determine the underlying cause. These findings warrant closer review and, potentially, additional testing to better understand what is contributing to the abnormal results, especially in someone with CVID.

Given the complexity of immune deficiency and its potential impact on blood counts, evaluation by a hematologist who is experienced in caring for patients with immune-mediated conditions is important. This type of expertise is more commonly found at academic or tertiary medical centers rather than in smaller community practices. Referral to a university-based or teaching hospital may provide access to specialists who routinely manage CVID and related hematologic issues.

For patients who do not have access to a local immunologist, several options may help identify appropriate specialty care:

- Large academic medical centers or teaching hospitals, which often have immunology and hematology specialists familiar with complex immune disorders
- Telehealth consultations, particularly with physicians licensed in multiple states or participating in interstate licensure agreements, which may allow for remote specialty input
- Shared-care models, where a specialist provides recommendations and oversight while a local physician manages routine monitoring and follow-up
- National patient advocacy organizations or professional medical societies, which may offer “find a specialist” tools or referral resources

While access can be challenging, connecting with a specialist experienced in CVID can help ensure abnormal labs are properly evaluated and that treatment decisions are guided by expertise in immune deficiency.

» Have a question? Email us at editor@IGLiving.com.
Your information will remain confidential unless permission is given.

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The Nature Prescription: Get Outside to Improve Your Health

By Mairead McConnell, PhD

WHEN IS the last time you took a nature break? How often do you stop to notice a bird outside your window, sit under the shade of a tree or immerse yourself in a beautiful natural landscape? Enjoying the outdoors is not only reserved for the experienced hiker or adventure sports-lover, nor is it limited to those who live in a specific geographic region. There is a growing body of research demonstrating that time spent in nature can have profound benefits for both physical and mental health. This has led some physicians and mental health providers to begin "prescribing" time in nature as a medical recommendation. While this is not a true prescription in the literal sense, it is an invitation to explore what feels possible — and how these benefits may be even more accessible than you realize.

The benefits. A number of studies have shown that a practice called "forest bathing" is associated with psychological benefits, including reductions in anxiety and depressive symptoms. Other studies have found benefits for physical health as well, including lower blood pressure, improved sleep, better cognitive function and reductions in stress hormones. These studies span forest-like environments, as well as urban green spaces, and show that in some cases, as little as 10 minutes spent in nature can have these beneficial effects.

> *There is a growing body of research demonstrating that time spent in nature can have profound benefits for both physical and mental health.*

The barriers. It is no surprise that as our time spent in front of screens increases, time spent outside decreases. In 2026, the average person spends more time online than ever before, and more people now live in urban environments with less immediate access to natural spaces. For those living with chronic illness or immunodeficiency, fatigue, pain flares, infection risk or mobility limitations can make even simple outings feel daunting. Even so, there may be creative ways for you to access the benefits of being outdoors without a major cost to your time, energy or wallet.

Where to begin:

1) Take a nature walk. From a short stroll in a city park to a hike in the wilderness, choose a route and amount that works for you. If walking outdoors is not at all accessible to you, consider sitting on a park bench or a porch where you have a view of the outdoors and can breathe in the fresh air.

2) Engage your senses. Being in nature invites us to engage the senses and be fully present in the experience. Next time you are outside, even for a moment, notice: What natural sounds do you hear? What beauty do you see? What scents do you smell?

3) Make it a regular habit. Like any healthy behavior, it is easier to remember and prioritize if you do it regularly. Consider stepping outside for a few minutes each morning or perhaps choosing one day a week to spend time in nature.

4) Some is better than none. Even just 10 minutes in nature breathing in fresh air can make a true difference for mood, brain health and overall well-being. It is not all-or-nothing. A little bit is a step in the right direction.

Connecting to the world. Remember, spending time in nature isn't about strength, endurance or perfection. It is about connection to the world around you and presence — even briefly. As the weather gets warmer and the days grow longer, give yourself permission to start small. Your body and mind will thank you. IG

MAIREAD MCCONNELL, PhD, is a clinical psychologist and assistant professor at Banner University Medical Center in Tucson, Ariz. She specializes in health psychology and is passionate about helping patients live well while navigating the challenges of chronic illness.

INDICATIONS AND USAGE

PANZYGA (Immune Globulin Intravenous [Human] – ifas) is indicated for the treatment of primary humoral immunodeficiency (PI) in patients 2 years of age and older, chronic immune thrombocytopenia (cITP) in adults and chronic inflammatory demyelinating polyneuropathy (CIDP) in adults.

PANZYGA is a liquid medicine for infusion that contains immunoglobulin G (IgG), which are proteins that help fight infection. It is made from human plasma that is donated by healthy people and contains antibodies. For patients with PI, PANZYGA helps replace the missing antibodies in the body. For patients with cITP, PANZYGA helps the body produce more platelets (the blood cells that help blood clot) to control or prevent bleeding. For patients with CIDP, PANZYGA may help improve mobility and hand strength.

PANZYGA is given into a vein (intravenously) in a hospital, infusion center, doctor’s office, or at home by a trained healthcare provider (HCP).

IMPORTANT SAFETY INFORMATION

WARNING: THROMBOSIS, RENAL DYSFUNCTION, and ACUTE RENAL FAILURE

See full prescribing information for complete BOXED WARNING

- **Thrombosis may occur with immune globulin intravenous (IGIV) products, including PANZYGA. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling vascular catheters, hyperviscosity, and cardiovascular risk factors.**
- **Renal dysfunction, acute renal failure, osmotic nephropathy, and death may occur with the administration of IGIV products in predisposed patients. Renal dysfunction and acute renal failure occur more commonly in patients receiving IGIV products containing sucrose. PANZYGA does not contain sucrose.**
- **For patients at risk of thrombosis, renal dysfunction, or acute renal failure, administer PANZYGA at the minimum infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk for hyperviscosity.**

Do not use PANZYGA if you:

- Have had a severe allergic reaction to immune globulin or other blood products
- Have a condition called selective (or severe) immunoglobulin A (IgA) deficiency, with antibodies against IgA and a history of hypersensitivity

What should I know before taking PANZYGA?

- PANZYGA can make vaccines (like measles/mumps/rubella or chickenpox vaccines) work less effectively for you. Before you get any vaccines, tell your healthcare provider that you take PANZYGA
- Decreased kidney function and kidney function failure can occur
- Severe headache, drowsiness, fever, painful eye movements, or nausea and vomiting can occur
- Elevated blood pressure can occur particularly in patients who have a history of hypertension (high blood pressure)
- If you are elderly, with heart or kidney problems, discuss with your healthcare provider prior to initiating treatment with PANZYGA
- PANZYGA is made from human blood and therefore may have a risk of transmitting infectious agents, including viruses and, theoretically, the variant Creutzfeldt-Jakob disease (CJD) and CJD agent. The production and manufacturing process reduces this risk, but the risk cannot be eliminated

PANZYGA can cause serious side effects. If any of the following problems occur after starting PANZYGA, stop the infusion immediately and contact your HCP or call emergency services:

- Hives, swelling in the mouth or throat, itching, trouble breathing, wheezing, fainting, or dizziness. These could be signs of a serious allergic reaction
- Bad headache with nausea, vomiting, stiff neck, fever, drowsiness, painful eye movements, and sensitivity to light. These could be signs of irritation and swelling of the lining around your brain

Please see Important Safety Information on this and adjacent page of this advertisement and Brief Summary of Prescribing Information.

FDA approved for chronic inflammatory demyelinating polyneuropathy (CIDP) in adults to improve neuromuscular disability and impairment

- **80% treated with 1g/kg and 92% treated with 2g/kg of PANZYGA saw improvement in arm and/or leg impairment[*]**
- **With the PANZYGA Co-Pay Program, eligible patients may pay as little as $0 for PANZYGA[†]**
  - Patients must have commercial insurance to be eligible
  - Patients are not eligible if they are enrolled in a state or federally funded insurance program

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Talk to your doctor about PANZYGA and learn more at PanzygaInfo.com

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[*] Depending on the ongoing therapy dose.

[†] Eligible, commercially insured patients may pay as little as $0 for PANZYGA and may receive a maximum benefit of $12,500 per year or the cost of patient's co-pay in a 12-month period (whichever is less) for claims received by the program. Terms and conditions/eligibility requirements apply. See full Terms and Conditions at PanzygaCoPay.com.

IMPORTANT SAFETY INFORMATION (continued)

- Reduced urination, sudden weight gain, or swelling in your legs. These could be signs of a kidney problem (decreased kidney function or kidney failure)
- Pain, swelling, warmth, redness, or a lump in your legs or arms. These could be signs of a blood clot, which could happen in the heart, brain, lungs, or elsewhere in the body
- Brown or red urine, swelling, fatigue, fast heart rate, difficulty breathing, or yellow skin or eyes. These could be signs of a liver or blood problem
- Chest pain or trouble breathing, or blue lips or extremities. These could be signs of a serious heart or lung problem
- Fever over 100°F. This could be a sign of an infection
- Headache, fatigue or confusion, vision problem, chest pain, difficulty breathing, irregular heartbeat, or pounding in your chest, neck, or ears. These could be signs of high blood pressure

Ask your HCP whether you should have rescue medications available, such as antihistamines or epinephrine.

What are the possible or reasonably likely side effects for PANZYGA?

The most common side effects that may occur with PANZYGA are:

- Headache
- Nausea
- Fever
- Increased blood pressure
- Dermatitis
- Fatigue
- Abdominal pain
- Dizziness
- Anemia

These are not all the possible side effects. Talk to your HCP about any side effect that bothers you or that does not go away.

Tell your HCP if you are pregnant, or plan to become pregnant, or if you are nursing.

Patients should always ask their doctors for medical advice about adverse events.

You may report an adverse event related to Pfizer products by calling 1-800-438-1985 (US only). If you prefer, you may contact the U.S. Food & Drug Administration (FDA) directly. The FDA has established a reporting service known as MedWatch where healthcare professionals and consumers can report problems they suspect may be associated with the drugs and medical devices they prescribe, dispense, or use. Visit www.fda.gov/MedWatch or call 1-800-FDA-1088.

PANZYGA® is a registered trademark of Octapharma AG.

PANZYGA is FDA approved for 3 indications:

CIDP in adults
PI in patients 2 years of age or older
cITP in adults

Manufactured by Octapharma Pharmazeutika Produktionsges m.b.H. Distributed by Pfizer Labs, Division of Pfizer inc.

PP-PAN-USA-0927

April 2024

panzyga®
Immune Globulin
Intravenous (Human) - ifas
10% Liquid Preparation

CONSUMER BRIEF SUMMARY
(PANZYGA: *pan-zee-guh*)

This brief summary highlights the most important information about PANZYGA. Please read it carefully before using PANZYGA and each time you have an infusion, as there may be new information. This brief summary does not take the place of talking with your healthcare provider about your medical condition or your treatment. If you have any questions after reading this, ask your healthcare provider. For more information, go to www.PanzygaInfo.com.

What is PANZYGA?

PANZYGA is a liquid medicine for infusion that contains immunoglobulin G (IgG), which are proteins that help fight infection. PANZYGA is used to treat primary humoral immunodeficiency (PI) in patients 2 years of age and older, chronic immune thrombocytopenia (cITP) in adults, and chronic inflammatory demyelinating polyneuropathy (CIDP) in adults.

PANZYGA is made from human plasma that is donated by healthy people and contains antibodies. For patients with PI, PANZYGA helps replace the missing antibodies in the body. For patients with cITP, PANZYGA helps the body produce more platelets (the blood cells that help blood clot) to control or prevent bleeding. For patients with CIDP, PANZYGA may help improve mobility and hand strength.

PANZYGA is given into a vein (intravenously) in a hospital, infusion center, doctor's office, or at home by a trained healthcare provider (HCP).

WARNING: THROMBOSIS, RENAL DYSFUNCTION, and ACUTE RENAL FAILURE

See full prescribing information for complete BOXED WARNING

- **Thrombosis may occur with immune globulin intravenous (IGIV) products, including PANZYGA. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling vascular catheters, hyperviscosity, and cardiovascular risk factors.**
- **Renal dysfunction, acute renal failure, osmotic nephropathy, and death may occur with the administration of IGIV products in predisposed patients. Renal dysfunction and acute renal failure occur more commonly in patients receiving IGIV products containing sucrose. PANZYGA does not contain sucrose.**
- **For patients at risk of thrombosis, renal dysfunction, or acute renal failure, administer PANZYGA at the minimum infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk for hyperviscosity.**

Who should NOT use PANZYGA?

Tell your healthcare provider if you:

- Have had a severe allergic reaction to immune globulin or other blood products
- Have a condition called selective (or severe) immunoglobulin A (IgA) deficiency, with antibodies against IgA and a history of hypersensitivity

PANZYGA can cause serious side effects. If any of the following problems occur after starting PANZYGA, stop the infusion immediately and contact your HCP or call emergency services:

- Hives, swelling in the mouth or throat, itching, trouble breathing, wheezing, fainting, or dizziness. These could be signs of a serious allergic reaction
- Bad headache with nausea, vomiting, stiff neck, fever, drowsiness, painful eye movements, and sensitivity to light. These could be signs of irritation and swelling of the lining around your brain
- Reduced urination, sudden weight gain, or swelling in your legs. These could be signs of a kidney problem (decreased kidney function or kidney failure)
- Pain, swelling, warmth, redness, or a lump in your legs or arms. These could be signs of a blood clot, which could happen in the heart, brain, lungs, or elsewhere in the body
- Brown or red urine, swelling, fatigue, fast heart rate, difficulty breathing, or yellow skin or eyes. These could be signs of a liver or blood problem
- Chest pain or trouble breathing, or blue lips or extremities. These could be signs of a serious heart or lung problem
- Fever over 100°F. This could be a sign of an infection
- Headache, fatigue or confusion, vision problem, chest pain, difficulty breathing, irregular heartbeat, or pounding in your chest, neck, or ears. These could be signs of high blood pressure

Ask your HCP whether you should have rescue medications available, such as antihistamines or epinephrine.

What should I know before taking PANZYGA?

- PANZYGA can make vaccines (like measles/mumps/rubella or chickenpox vaccines) work less effectively for you. Before you get any vaccines, tell your healthcare provider that you take PANZYGA
- Decreased kidney function and kidney function failure can occur
- Severe headache, drowsiness, fever, painful eye movements, or nausea and vomiting can occur
- Elevated blood pressure can occur particularly in patients who have a history of hypertension (high blood pressure)
- If you are elderly, with heart or kidney problems, discuss with your healthcare provider prior to initiating treatment with PANZYGA
- PANZYGA is made from human blood and therefore may have a risk of transmitting infectious agents, including viruses and, theoretically, the variant Creutzfeldt-Jakob disease (CJD) and CJD agent. The production and manufacturing process reduces this risk, but the risk cannot be eliminated

What are the possible or reasonably likely side effects for PANZYGA?

The most common side effects that may occur with PANZYGA are:

- Headache
- Nausea
- Fever
- Increased blood pressure
- Dermatitis
- Fatigue
- Abdominal pain
- Dizziness
- Anemia

These are not all the possible side effects. Talk to your HCP about any side effect that bothers you or that does not go away. Tell your HCP if you are pregnant, or plan to become pregnant, or if you are nursing. If you encounter any problems or experience side effects during or after the infusion, contact your healthcare provider. When doing so, keep your therapy tracker with you to be able to give all necessary information.

Patients should always ask their doctors for medical advice about adverse events.

You may report an adverse event related to Pfizer products by calling 1-800-438-1985 (US only). If you prefer, you may contact the US Food and Drug Administration (FDA) directly. The FDA has established a reporting service known as MedWatch where healthcare professionals and consumers can report problems they suspect may be associated with the drugs and medical devices they prescribe, dispense, or use. Visit www.fda.gov/MedWatch or call 1-800-FDA-1088.

This brief summary is based on the PANZYGA Prescribing Information (February 2021).

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Distributed by Pfizer Labs, Division of Pfizer Inc.

SARS-CoV-2 and COVID-19: Vaccination Part 3

By Terry O. Harville, MD, PhD

IN THE last issue, we introduced the two major mRNA vaccines made by Pfizer-BioNTech (Comirnaty) and Moderna (Spikevax). Indeed, since that discussion, several new studies have been published demonstrating extreme benefit from mRNA vaccinations for COVID-19. For example, one study demonstrated that persons aged 18 to 59 years had an overall decrease in all forms of death if vaccinated versus persons not vaccinated. Thus, once again, the politicalization of COVID-19 vaccination is totally misguided since vaccination provides benefit and prevents "all forms of death."

The World Health Organization currently recognizes 12 COVID-19 vaccines, many of which were developed early in the pandemic: three protein subunit vaccines (Nuvaxovid, Covovax and SKYCovione), two mRNA (Spikevax by Moderna and Comirnaty by Pfizer-BioNTech), four non-replicating viral vector vaccines (Convidecia, Jcovden, Vaxzevria and Covishield) and three inactivated virus vaccines (Covaxin, Covilo and CoronaVac). These vaccines were licensed for use in various countries, but except for the two mRNA vaccines and the protein subunit vaccine (Novavax), they are not approved for use in the United States.

Another early-developed, but abandoned vaccine, was the Johnson and Johnson/Janssen COVID-19 vaccine. It used components of the SARS-CoV-2 genome incorporated into a "harmless" adenovirus vector to deliver the SARS-CoV-2 components into cells to produce protein and to then induce antibody production. At first glance, this seemed more similar to traditional vaccines and was released about the same time as the mRNA vaccines. Thus, many selected this route over the new mRNA vaccines, since it seemed to be a familiar vaccination approach back in 2021. Unfortunately, the Johnson and Johnson/Janssen COVID-19 vaccine induced hypercoagulability (increased clot formation), and many middle-aged women developed strokes. It was proposed that autoantibody production, specifically to platelet factor 4, had a role in this. As we have discussed multiple times, the anti-ACE2 antibody that we discovered, which also appears to have a role in microclotting, may also have a contributing role. The bottom line is that vaccines depending "directly" on protein from the spike or receptor-binding domain of SARS-CoV-2 may not be good targets as a strategy for antibody production due to increased risk for autoantibody production.

Overall, the mRNA vaccines were reported to be more than 80 to 95 percent successful against COVID-19, whereas the other vaccine forms were more in the 50 percent success range. Different studies showed different levels of benefit. There may be a reasonable explanation for this.

Vaccination is used to mimic the normal immune response to exposure to an antigen. The process proceeds as follows: The antigen (protein, which is considered foreign to the body, possibly from a pathogen to which the immune system would like to respond) is introduced to the body. This could be from infection or injection, as with vaccination. Tissue macrophages and dendritic cells engulf the antigen. The dendritic cell with antigen on board begins processing the protein antigen into peptides generally in the range of 14 to 18 amino acids in length, and also begins migration to a lymph node in the vicinity. For example, vaccination in the arm results in dendritic cells going to the lymph nodes in the armpit. Once there, T lymphocytes, which can recognize the peptide antigens are recruited and, likewise, B lymphocytes are recruited. The recognizing T lymphocytes send signals to the B lymphocytes, which can also recognize the peptide antigen, which induces specific antibody production.

In the next issue, we will continue the discussion of antibody production and how mRNA vaccination is superior to protein immunization.

Reference

1. Semenzato, L, Le Vu, S, Botton J, et al. COVID-19 mRNA Vaccination and 4-Year All-Cause Mortality Among Adults Aged 18 to 59 Years in France. *JAMA Network Open*, 2025;8(12):e2546822. Accessed at jamanetwork.com/journals/jamanetworkopen/fullarticle/2842305.

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Differentiating Between Bacterial, Viral and Fungal Infections

By Michelle Greer, RN, IgCN

THE IMMUNE system is complex, consisting of a vast variety of organs and cells that protect the body from foreign invaders, including bacteria, viruses and fungi. Infection from these pathogens may be aggressive and life-threatening or nonhostile and relatively mild and short-term (Table). All pathogens infect one cell or one tissue, then spread around the body and infect multiple other cells or tissues. They may be transmitted through the air, physical contact or exposure to body fluids. The body generates resistance to pathogens via antibodies that fight the infection.

Table: Bacterial, Viral and Fungal Infection Examples

Condition	Pathogen Name	Pathogen Type
Common cold	Rhinovirus	Virus
Ebola hemorrhagic fever	Ebolavirus	Virus
Encephalitis	Flavivirus	Virus
	Herpes simplex	Virus
Gastric ulcer	Helicobacter pylori	Bacterium
Gonorrhea	Neisseria gonorrhoeae	Bacterium
Hepatitis	Hepatitis B virus	Virus
HIV/AIDS	Lentivirus	Virus
Influenza	Influenza virus	Virus
Lyme disease	Borrelia burgdorferi	Bacterium
Meningitis	Meningococci	Bacterium
	Streptococci	Bacterium
	Enterovirus	Virus
	Herpes simplex type 2	Virus
	Cryptococcal	Fungus
Mycosis	Tinea versicolor	Fungus
Pneumonia	Pneumococci	Bacterium
	Streptococci	Bacterium
	Coronavirus	Virus
	Rhinovirus	Virus
Meningitis	Meningococci	Bacterium
	Streptococci	Bacterium
	Enterovirus	Virus
	Herpes simplex type 2	Virus
	Cryptococcal	Fungus
Syphilis	Treponema pallidum	Bacterium

Reference: Cole, L. *Human Physiology, Biochemistry and Basic Medicine*, 2015 Oct 30:193–196. Accessed at pmc.ncbi.nlm.nih.gov/articles/PMC7173549/table/t0010.

While there is overlap among these infectious agents, there are many differences in how they behave, how long infections last and how the body responds to them. Understanding the differences among bacterial, viral and fungal infections can aid in navigating symptoms and interventions for quicker and more effective recovery.

Bacteria

Bacteria are living, single-celled organisms. They do not have a nucleus, but are fully capable of surviving and reproducing on their own. Many bacteria living on the skin and in the gut help protect the human body.

However, some bacteria are harmful. When harmful bacteria enter the body, they multiply and trigger inflammation — this is a bacterial infection. Bacteria replicate by “binary fission,” meaning one cell splits into two cells. Under the right conditions, this can happen quickly. Bacterial infections often come on suddenly and can worsen rapidly.

- *Symptoms*: Fever, chills and fatigue are common. Additional symptoms depend on type and location of the infection:
  - Respiratory: Cough, sore throat, congestion, shortness of breath
  - Gastrointestinal: Diarrhea, nausea, vomiting, stomach pain, cramps
  - Urinary: Burning during urination, cloudy urine, frequent urination
  - Skin: Blisters, ulcers, red streaks

Symptoms may be intense but often improve quickly once the right treatment begins. Bacterial infections often cause strong, localized inflammation, which may be more severe or take longer to resolve in people with chronic conditions.

- *Treatment*: Antibiotics kill bacteria or stop them from reproducing. There are some vaccines for bacteria such as tetanus and pneumococcal infection.

Viruses

Viruses are not living organisms and cannot reproduce on their own; rather, they are tiny particles made of genetic material (DNA or RNA) wrapped in a protein shell. To survive, they must have a host, so they invade and infect living cells to function. Once inside a host cell, a virus forces the infected cell to make copies of the virus. When enough new viruses are produced, the cell often dies, releasing the viruses to infect other cells. Viral infections often spread quickly through the body.

- *Symptoms*: Fever, fatigue and body aches are common. Some viral illnesses are short-lived (such as the common cold), while others can become chronic or latent, meaning the virus remains in the body long-term (for example, herpes viruses). Viral infections often cause widespread inflammation rather than localized infection. Much of the discomfort one experiences after contracting a virus comes from the immune system's response, not direct damage to the body from the virus itself. In people with chronic illness, this immune activation can worsen fatigue, pain or autoimmune symptoms.
- *Treatment*: Antivirals exist for some viruses but are limited. Antibiotics do not work against viruses. Many viruses are preventable with vaccines such as those formulated against influenza, COVID-19 and hepatitis. Treatment is often supportive, focusing on rest, hydration and symptom relief.

Fungi

Fungi are complex living organisms that have a nucleus like human cells. They include yeasts and molds. Many fungi live harmlessly in the environment or on the body. However, fungal infections often occur when fungi overgrow or enter parts of the body they normally wouldn't enter. They replicate by budding (yeasts) or producing spores (molds). Fungal infections often cause low-grade, persistent inflammation.

- *Symptoms*: Fungal infections tend to be slow-growing and chronic. Symptoms may develop gradually and linger for weeks or months, especially in people with weakened immune systems or chronic conditions.
- *Treatment*: Fungal infections can be treated with antifungal medications that can be topical or oral. Treatment for fungal infections often takes longer than for bacterial infections. Fungal infections are not treated with antibiotics and, in fact, are more common after antibiotic use, which disrupts protective bacteria. For example, yeast infections can occur in women.

A Word on Inflammation

Inflammation is one natural way the immune system reacts to defend and heal itself, but when that inflammation is excessive or prolonged, it can cause other issues and worsen existing chronic conditions. Bacterial infections tend to trigger inflammatory responses, viral infections can cause a more widespread immune response and fungal infections often drive slow, persistent inflammation. For people with chronic and/or autoimmune conditions, this inflammatory burden can increase symptom flares and make infections harder to resolve.

Fever is one of the body's most common responses to infection. It reflects the immune system releasing inflammatory signals to help slow the growth of bacteria and viruses and improve immune cell function. Overall, inflammation plays a central role in how ill patients feel and how long recovery takes.

Mitigate Risk and Seek Medical Advice

Prevention measures are important for everyone. They include frequent and proper handwashing and hand care, appropriate use of masks, respiratory etiquette (covering coughs) and just staying home when sick.

The type of pathogen responsible for infection may not be immediately apparent, so it's important to seek medical advice and intervention when symptoms are severe, persistent or worsening. Healthcare providers will do a more extensive assessment and order tests to identify the cause of infection and determine an appropriate course of treatment, which can reduce complications, limit prolonged inflammation and lead to a quicker recovery. IG

MICHELLE GREER, RN, IgCN, is senior vice president of sales at Nufactor, a specialty infusion company.

GUIDANCE

IDF Provides PI Vaccine Guidance After CDC Revision to Vaccine Guidelines

After the Centers for Disease Control and Prevention (CDC) revised its guidelines for childhood vaccinations, the Immune Deficiency Foundation (IDF), on its website, is offering the following clarification and guidance to aid the primary immunodeficiency (PI) community in making the best possible decisions:

- While CDC no longer recommends children receive the COVID-19, hepatitis A, hepatitis B, meningococcal ACWY, meningococcal B, respiratory syncytial virus (RSV), dengue [previously universally recommended in Puerto Rico, American Samoa, U.S. Virgin Islands, Federated States of Micronesia, Republic of Marshall Islands and the Republic of Palau only] and rotavirus vaccines (the latter two are live, attenuated vaccines), these vaccines are still available to all children through shared clinical decision-making. And, private and public insurance must still cover the full costs of these vaccines, with no out-of-pocket costs to families, if caregivers and providers agree that the child should receive the vaccines.
- All immunocompromised children should receive vaccines included in the American Academy of Pediatrics (AAP) schedule that their healthcare providers, in consultation with their immunologist, recommend they receive. Even though children may be receiving immune globulin (IG) replacement therapy, it may not provide protective antibody levels to some pathogens such as influenza, COVID-19 or whooping cough (pertussis). And, most people with PI can make at least some antibodies, even if they have an antibody deficiency. In addition, some vaccines induce T cell immunity, which is especially important for protection against viruses. Further, most children with PI can safely receive nonviable vaccines, and some children with PI can also safely receive live, attenuated vaccines, such as varicella (chickenpox) and measles, mumps and rubella (MMR). Therefore, caregivers should discuss this with their child's immunologist.

  However, babies who have had an abnormal TREC newborn screening test, who are undergoing testing for a significant T cell deficiency, or who have a family member with a significant T cell deficiency that has not yet been ruled out in the baby should not receive any live, attenuated vaccines.
- Children who are close contacts of people with PI (e.g., family or household members) should receive all vaccines recommended for their age by AAP unless they have another contraindication. This is because being surrounded by people who are fully vaccinated decreases the chances that a person with PI will come in contact with a vaccine-preventable infectious disease.

To view the complete IDF guidance, access its website at primaryimmune.org/resources/news-articles/foundation-provides-guidance-amid-changing-vaccine-recommendations.

Immune Deficiency Foundation. Foundation Provides Guidance Amid Changing Vaccine Recommendations, Jan. 13, 2026. Accessed at primaryimmune.org/resources/news-articles/foundation-provides-guidance-amid-changing-vaccine-recommendations.

CAMPAIGNS

Quest Diagnostics Joins IDF in PI Awareness Campaign

Quest Diagnostics has joined the Immune Deficiency Foundation (IDF) on a new wellness initiative to raise awareness of primary immunodeficiency diseases and improve access to treatments. The collaboration comes as part of the Quest Diagnostics Season of Giving Program, reflecting both organizations' commitment to supporting patients and families affected by primary immunodeficiency. Quest Diagnostics brings extensive expertise in diagnostic testing and laboratory services to advance IDF's mission of serving the primary immunodeficiency community.

"We are thrilled to welcome Quest Diagnostics," said Jorey Berry, IDF president and CEO. "Their commitment to diagnostic excellence and patient care aligns perfectly with our mission. We're grateful for companies who share our dedication to bringing hope to families affected by primary immunodeficiencies and awareness to a rare, chronic and often misdiagnosed condition."

Through this collaboration, Quest Diagnostics and IDF will work together to advance awareness of primary immunodeficiency by sharing resources and information at select locations, improve access to critical diagnostic resources and support educational initiatives and volunteer opportunities for employees.

Immune Deficiency Foundation. Immune Deficiency Foundation Welcomes Quest Diagnostics in Awareness Campaign. Accessed at primaryimmune.org/resources/news-articles/new-awareness-campaign-quest-diagnostics.

MEDICINES

FDA Approves First Gene Therapy Treatment for Wiskott-Aldrich Syndrome

The U.S. Food and Drug Administration (FDA) has approved Waskyra (etuvetidigene autotemcel), the first cell-based gene therapy for the treatment of Wiskott-Aldrich syndrome (WAS). Waskyra is indicated for pediatric patients 6 months and older and adults with WAS who have a mutation in the WAS gene and for whom hematopoietic stem cell transplantation (HSCT) is appropriate and no suitable human leukocyte antigen (HLA)-matched related stem cell donor is available.

The safety and effectiveness of Waskyra was assessed based on two open-label, single-arm, multinational clinical studies and an expanded access program totaling 27 patients with severe WAS, which demonstrate substantial and sustained clinical benefit for patients with severe WAS, with significant reductions in the primary disease manifestations that drive morbidity and mortality.

The rate of severe infections decreased by 93 percent in the six to 18 months post-treatment period compared to the rate 12 months before treatment. Similarly, moderate and severe bleeding events were reduced by 60 percent in the first 12 months post-treatment compared to the year prior to treatment. Most patients did not report moderate to severe bleeding after four years post treatment.

The most common side effects associated with Waskyra include rash, respiratory tract infection, febrile neutropenia, catheter related infection, vomiting, diarrhea, liver injury and petechiae.

"Today's approval addresses the urgent need in the WAS community, where patients have described living 'a life of terrifying worry and fear' without any approved therapies available," said Vijay Kumar, MD, acting director of the CBER Office of Therapeutic Products. "This action marks significant progress in the development of much-needed treatment options for patients affected by this debilitating and life-threatening disease, enabling them to engage in everyday activities such as going to school or participating in sports."

FDA Approves First Gene Therapy Treatment for Wiskott-Aldrich Syndrome. U.S. Food and Drug Administration press release, Dec. 9, 2025. Accessed at www.fda.gov/news-events/press-announcements/fda-approves-first-gene-therapy-treatment-wiskott-aldrich-syndrome#:~:text=The%20U.S.%20Food%20and%20Drug,%2DAldrich%20syndrome%20(WAS).

CAMPAIGN

'Bubble Boy' Music Aims to Raise Awareness of SCID

To help raise awareness of severe combined immune deficiency (SCID) and to promote hematopoietic stem cell transplantation (HSCT), University of Alberta (Canada) music professor Michael Frishkopf composed a piece of music based on the disease.

The idea stemmed from a child named Jakob, the son of Canadians Andrea Fernández and Kamil Guziak who was diagnosed with SCID. At the time, HSCT was not an approved treatment in Canada, and Jakob was not a candidate for a bone marrow transplant from a sibling because he is an only child. Jakob did eventually receive HSCT therapy.

Frishkopf composed the music using sonification, a process that renders data, such as genetic sequences, into sound or music. Sonification provided the sequence of the ADA gene, composed of over 32,000 letters, all varying combinations of A (adenine), T (thymine), G (guanine) and C (cytosine), the building blocks of all DNA. He identified the longest repeating substring of 64 letters — call it a motif — and interpreted each letter as a musical interval. The problem was it didn't make musical sense. So, to strike an effective balance between representing the data and infusing his own creative interpretation, Frishkopf confined the intervals to a C scale in the Dorian mode, and arrived at a melody within a reasonable range. "From there, it's just me interpreting," he says — a little like Paul Williams, but with lyrics provided by Jakob's mother Andrea and a little flute added for variety.

Andrea's lyrics capture the family's struggle to keep Jakob alive: "In the middle of my dreams, you're holding my hand tight … I'm not ready to lose you now, together we can fight."

Jakob's Melody can be listened to at www.ualberta.ca/en/folio/2025/02/u-of-a-professor-turns-genetic-marker-for-bubble-boy-disease-into-music.html.

McMaster, G. U of A Professor Turns Genetic Marker for 'Bubble Boy Disease' Into Music. University of Alberta news, Feb. 4, 2025. Accessed at www.ualberta.ca/en/folio/2025/02/u-of-a-professor-turns-genetic-marker-for-bubble-boy-disease-into-music.html.

MEDICINES

Novartis’ Ianalumab Granted FDA Breakthrough Therapy Designation for Sjögren’s Disease

The U.S. Food and Drug Administration (FDA) has granted breakthrough therapy designation to ianalumab for Sjögren’s disease. Ianalumab is a fully human monoclonal antibody with a novel dual mechanism of action that depletes B cells and inhibits their activation and survival via BAFF-R blockade.

“This breakthrough therapy designation recognizes the potential for ianalumab to substantially improve the standard of care for people with Sjögren’s disease, who currently don’t have effective treatment options for this debilitating disease,” said Angelika Jahreis, MD, PhD, global head of development, immunology, at Novartis. “We look forward to working with the agency through the regulatory review process with the hope of making ianalumab available to appropriate patients as quickly as possible.”

The designation is supported by positive data from multiple studies, including replicate Phase III trials NEPTUNUS-1 and NEPTUNUS-2, which delivered a clinically meaningful benefit, showing improvement in disease activity and reductions in patient burden. Ianalumab demonstrated a favorable safety profile with an overall incidence of adverse events and serious adverse events comparable to placebo in both studies.

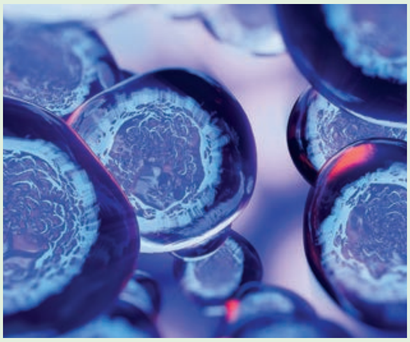
Novartis plans to submit ianalumab for regulatory approval globally starting in early 2026. If approved, ianalumab would become the first targeted treatment for patients with Sjögren’s disease.

U.S. FDA Grants Breakthrough Therapy Designation to Novartis’ Ianalumab for Sjögren’s Disease. Pharmabiz, Jan. 19, 2026. Accessed at www.pharmabiz.com/NewsDetails.aspx?aid=183640&sid=2.

RESEARCH

Stem Cell Discovery May Lead to Next-Generation Living Drugs

Researchers at the University of British Columbia (UBC) have demonstrated how to reliably produce an important type of human immune cells — helper T cells — from stem cells, a discovery that may lead to more accessible and effective off-the-shelf treatments for many conditions such as cancer, infectious diseases, autoimmune disorders and more.



“Engineered cell therapies are transforming modern medicine,” said co-senior author Peter Zandstra, PhD, professor and director of the UBC School of Biomedical Engineering. They reprogram human immune cells to recognize and attack illness, essentially turning the cells into “living drugs.” Most are made from a patient’s own immune cells, requiring weeks of customized manufacturing for each patient. These therapies are complex, expensive and often inaccessible.

Cell therapies work best when both killer T cells and helper T cells are present, but producing helper T cells in a laboratory setting has not been successful until recently. According to Dr. Zandstra, “This study addresses one of the biggest challenges in making these lifesaving treatments accessible to more people, showing for the first time a reliable and scalable way to grow multiple immune cell types.”

The researchers say the ability to generate both helper and killer T cells — and to control the balance between them — will significantly improve the efficacy of stem cell-grown immune therapies in the future. “This is a major step forward in our ability to develop scalable and affordable immune cell therapies,” said Dr. Zandstra.

Goldhawk, B. Stem Cell Engineering Breakthrough Paves Way for Next-Generation Living Drugs. UBC News, Jan. 8, 2026. Accessed at news.ubc.ca/2026/01/stem-cell-engineering-helper-t-cells.

RESEARCH

Early Exposure to Tobacco Smoke May Increase Chance of Autoimmune Disease

Early exposure to tobacco smoke, beginning as early as the prenatal period, may increase the likelihood of developing systemic autoimmune rheumatic diseases (SARDs), according to study findings published in *Seminars in Arthritis & Rheumatism*.

In a recent case-control study, researchers evaluated whether pregnancy complications, early childhood characteristics and tobacco-related exposures were associated with juvenile- or adult-onset SARDs. Data were drawn from 329 children, including 124 probands (the first individuals in a family identified with a genetic condition), 115 unaffected siblings and 90 unrelated control individuals, along with 184 adults (76 probands, 63 unaffected siblings and 45 unrelated control individuals).

Eighty percent of pediatric probands had juvenile idiopathic inflammatory myopathies, and 64 percent of adults had idiopathic inflammatory myopathies. Sex distribution, race and parental or participant education were similar across comparison groups.

Among children, no single pregnancy complication was significantly associated with disease onset; however, juvenile probands had a greater overall number of pregnancy complications compared with unrelated control individuals. Other early-life characteristics — including birth season, birth order, breastfeeding and use of soy formula — did not differ significantly between probands and control individuals.

More pronounced differences emerged for smoking exposures. Juvenile probands had higher rates of in utero tobacco exposure compared with unrelated control individuals. Early-life household smoking before age 3 years was also more common among juvenile probands. Paternal smoking during pregnancy demonstrated the strongest association.

In adult-onset disease, early-life household smoking before age 10 years was significantly more common among probands than unaffected siblings. Personal smoking history did not differ significantly when age was included as a covariate.

To further account for genetic susceptibility, analyses restricted to White participants showed that HLA-DRB1*03:01 was more frequent among both juvenile- and adult-onset probands. When smoking exposures and HLA-DRB1*03:01 were evaluated together, early-life household smoking remained associated with SARDs among both age groups, suggesting an effect independent of genetic predisposition.

The study authors concluded, "These findings underscore the importance of modifiable early environmental exposures in the pathogenesis of autoimmune diseases."

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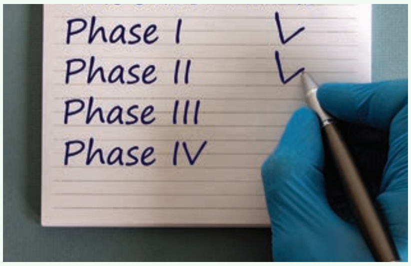
MEDICINES

Argenx SE Reports Promising Phase II Results for Efgartigimod in Autoimmune Diseases



Argenx SE announced positive results from Phase II studies of its drug efgartigimod. The studies demonstrated significant improvements in patients with myositis and Sjogren's disease, with efgartigimod showing potential as a precision therapy. The drug has also received fast track designation from the U.S. Food and Drug Administration for Sjogren's disease, highlighting its potential impact on the treatment landscape for these autoimmune conditions.

argenx Presents New Efgartigimod Data at EULAR 2025 Highlighting Positive Phase 2 Proof-of-Concept Results in Myositis and Sjogren's Disease. argenx press release, June 11, 2025. Accessed at argenx.com/news/2024/argenx-presents-new-efgartigimod-data-at-eular-2025-highlighting#.

WITH XEMBIFY FOR PI,

COUNT ON MORE GOOD DAYS*

Whether you've received IG therapy before or not, XEMBIFY offers reliable infection protection with flexible dosing to fit into your life.[1-3]

IG, immune globulin; PI, primary immunodeficiency disease.

IMPORTANT SAFETY INFORMATION

WARNING: THROMBOSIS

- **Thrombosis (formation of blood clots within blood vessels) may occur with immune globulin products, including XEMBIFY. Before you take XEMBIFY, talk to your doctor if you:**
    - **Are older**
    - **Are sedentary (need to lie down or sit down) for long periods of time**
    - **Are taking estrogen-containing medicines (birth control pills, hormone replacement therapy)**
    - **Have a permanent intravenous (IV) catheter**
    - **Have hyperviscosity of the blood (diseases such as multiple myeloma or other causes of elevated proteins in the blood)**
    - **Have cardiovascular (heart) problems or previous history of stroke**
- **Thrombosis may occur even if you don't have any risk factors**
- **If you are at risk of thrombosis, your doctor may prescribe XEMBIFY at the minimum dose and infusion rate. Make sure you drink plenty of fluid before taking XEMBIFY. Make sure your doctor is checking you regularly for signs and symptoms of thrombosis and is checking your blood viscosity if you are at risk of hyperviscosity**

What is XEMBIFY®?

XEMBIFY® (immune globulin subcutaneous human–klhw) is a 20% immune globulin used in the treatment of primary humoral immunodeficiency disease (PIDD) in patients 2 years of age and older. XEMBIFY is for subcutaneous administration only.

Who should not use XEMBIFY?

- XEMBIFY should not be used if you have had a severe allergic reaction to human immune globulin, or if you have been told by a doctor that you are IgA deficient and have developed antibodies to IgA and hypersensitivity after exposure to a previous plasma product

What are possible serious side effects of XEMBIFY?

- **Aseptic meningitis syndrome (AMS).** Aseptic meningitis is a non-infectious inflammation of the membranes that cover the brain. It causes a severe headache syndrome, which may occur with human immune globulin treatment, including XEMBIFY. If you are showing signs and symptoms of AMS, your doctor may conduct a thorough neurological evaluation including spinal tap (sampling fluid which surrounds the spinal cord) to rule out other causes of meningitis. Stopping human immune globulin treatment has resulted in the end of signs and symptoms within several days. Treatment may include analgesics (pain medicines) and/or a special procedure known as a "blood patch" to stop headache
- **Hypersensitivity.** Severe allergic reactions may occur with immune globulin products, including XEMBIFY. If you have a severe allergic reaction, stop the infusion immediately and

GRIFOLS

January 2026 US-XEM-2500119

COUNT ON THE POWER OF
PURE PROTECTION

Xembify®
(immune globulin subcutaneous human-klhw) 20%

INFECTION PROTECTION YOU CAN TRUST WITH PROVEN TOLERABILITY[1,2]

*In a clinical study, people taking XEMBIFY had[2]:

- **0** serious bacterial infections[†‡]
- **0** hospitalizations due to infection[‡]
- Fewer than 3 days of work or school missed due to infections

[†] One patient reported sepsis due to an animal bite, an event deemed unrelated to treatment.[2]
[‡] Rate per subject-year: 0.049.[2]

Count on XEMBIFY
for the power of pure protection.[1,2,4]
Scan the code or visit XEMBIFY.com

get medical attention. XEMBIFY contains IgA. If you have known antibodies to IgA, you may have a greater risk of developing potentially severe allergic reactions

- **Kidney problems or failure.** Kidney problems or failure may occur with use of human immune globulin products, especially those containing sucrose (sugar). XEMBIFY does not contain sucrose. If you have kidney disease or diabetes with kidney involvement, your doctor should perform a blood test to assess your hydration level and kidney function before beginning immune globulin treatment and at appropriate intervals thereafter. If your doctor determines that kidney function is worsening, they may discontinue treatment
- **Hemolysis.** Your doctor should monitor you for symptoms of hemolysis (destruction of red blood cells causing anemia, or low red blood cell count). If your doctor suspects hemolysis, they should perform additional tests to confirm
- **Transfusion-related acute lung injury (TRALI).** TRALI is a rare but serious syndrome characterized by sudden acute respiratory distress following transfusion. If your doctor suspects TRALI, they will monitor you for any other lung issues. TRALI may be managed with oxygen therapy
- **Transmissible infectious agents.** Because XEMBIFY is made from human blood, it may carry a risk of transmitting infectious agents such as viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent, and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent. No cases of transmission of viral diseases or CJD have been associated with the use of XEMBIFY
- **Interference with lab tests.** Because XEMBIFY contains a variety of antibodies, blood tests to determine antibody levels may be falsely elevated. Be sure to tell your doctor or lab technician that you are using XEMBIFY

What are other possible side effects of XEMBIFY?

- In clinical studies of XEMBIFY, some patients experienced local side effects (at the injection site) including pain, redness, puffiness, bruising, nodules, itching, firmness, scabbing and swelling at the site on the skin where the injection occurred. Some patients experienced non-injection-site side effects including cough and diarrhea
- Use of XEMBIFY may interfere with the immune response to virus vaccines, such as vaccines for measles, mumps, rubella and varicella. Tell your doctor you are taking XEMBIFY before getting vaccinations

Please see brief summary of the full Prescribing Information on the following page or visit XEMBIFY.com for the full Prescribing Information.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

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XEMBIFY®

XEMBIFY (immune globulin subcutaneous, human – klhw) 20% solution

HIGHLIGHTS OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use XEMBIFY safely and effectively. See full prescribing information for XEMBIFY.

XEMBIFY (immune globulin subcutaneous, human – klhw)
20% solution

Initial U.S. Approval: 2019

WARNING: THROMBOSIS
See full prescribing information
for complete boxed warning.

- **Thrombosis may occur with immune globulin products, including XEMBIFY. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling vascular catheters, hyperviscosity, and cardiovascular risk factors. Thrombosis may occur in the absence of known risk factors.**
- **For patients at risk of thrombosis, administer XEMBIFY at the minimum dose and infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk for hyperviscosity.**

RECENT MAJOR CHANGES

Dosage and Administration, Dose	7/2024
Dosage and Administration, Administration	7/2024

INDICATIONS AND USAGE

XEMBIFY® (immune globulin subcutaneous, human-klhw) is a 20% immune globulin solution for subcutaneous injection indicated for treatment of Primary Humoral Immunodeficiency (PI) in patients 2 years of age and older.

DOSAGE AND ADMINISTRATION

For subcutaneous infusion only

Dose

XEMBIFY can be administered at regular intervals from daily up to every two weeks (biweekly).

- Switching to XEMBIFY from intravenous immune globulin (IVIG): If a patient is switching to XEMBIFY, obtain the patient's serum IgG trough level to guide subsequent dose adjustments.
  Establish the initial weekly dose in grams by converting the monthly (or every 3 weeks) IVIG dose into an equivalent weekly dose and increasing it by using a dose adjustment factor (1.37)

  $$\text{Initial weekly dose (grams)} = \frac{\text{Prior IVIG dose (in grams)} \times 1.37}{\text{Number of weeks between IVIG doses}}$$

  - Weekly: Begin XEMBIFY one week after last IVIG infusion.
  - Frequent dosing (2-7 times per week): Divide the calculated weekly dose by the desired number of times per week.
  - Biweekly dosing (every 2 weeks): Multiply the weekly dose by 2.
- Switching to XEMBIFY from subcutaneous immune globulin (IGSC): Administer the same weekly dose (grams) as the weekly dose of prior IGSC treatment (grams).
- Treatment-naïve patients: For patients starting IgG replacement (not switching from IVIG or IGSC) administer loading doses of 150 mg/kg/day for 5 consecutive days, followed by weekly administrations starting at Day 8 at 150 mg/kg/week. Monitor IgG trough levels frequently every 2 weeks during first 8 weeks.

Administration

Infusion sites: up to 6 infusion sites simultaneously, with at least 2 inches (5 cm) between sites avoiding bony prominences, visible blood vessels, scars, and any areas of inflammation (irritation) or infection. Rotate sites for each administration.

Patient Age	Maximum Volume (mL/infusion site)	Infusion Rate (mL/hr/infusion site)
Children 2 to <10 years	25	≤25
Adults, children ≥10 years	25	≤35

DOSAGE FORMS AND STRENGTHS

XEMBIFY is a solution containing 0.2 g/mL (200 mg/mL; 20%) protein solution for subcutaneous infusion.

CONTRAINDICATIONS

- Anaphylactic or severe systemic reactions to human immunoglobulin or inactive ingredients of XEMBIFY such as polysorbate 80.
- IgA deficient patients with antibodies against IgA and a history of hypersensitivity.

WARNINGS AND PRECAUTIONS

- Aseptic Meningitis Syndrome (AMS) occurs within two days of treatment.
- Hypersensitivity and anaphylactic reactions may occur. IgA deficient patients with antibodies against IgA are at greater risk of developing severe hypersensitivity or anaphylactic reactions.
- Monitor for renal function in patients at risk for renal failure.
- Hemolysis can develop. Risk factors include high doses and non-O blood group. Closely monitor for hemolysis and hemolytic anemia.
- Monitor patients for pulmonary adverse reactions (transfusion-related acute lung injury [TRALI]).
- XEMBIFY is made from human plasma and may carry a risk of transmitting infectious agents, e.g., viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.
- Passive transfer of antibodies may confound serologic testing.

ADVERSE REACTIONS

The most common adverse reactions in ≥ 5% of patients in the clinical trial were local adverse reactions including infusion site erythema (redness), infusion site pain, infusion site swelling (puffiness), infusion site bruising, infusion site nodule, infusion site pruritus (itching), infusion site induration (firmness), infusion site scab, infusion site edema, and systemic reactions including cough and diarrhea.

To report SUSPECTED ADVERSE REACTIONS, contact Grifols Therapeutics LLC at 1-800-520-2807 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

DRUG INTERACTIONS

The passive transfer of antibodies may transiently interfere with the response to live virus vaccines, such as measles, mumps, rubella, and varicella.

USE IN SPECIFIC POPULATIONS

Geriatric: In patients over 65 years, do not exceed the recommended dose and infuse XEMBIFY at the minimum rate practicable.

Manufactured by:
GRIFOLS
Grifols Therapeutics LLC
Research Triangle Park, NC 27709 USA
U.S. License No. 1871

3067886
Revised 7/2024

RESEARCH

Study Reveals Potential New Method for Treating Autoimmune Disease

A team of researchers at Swansea University have found that targeting a protein that helps regulate energy production in immune cells may treat certain autoimmune diseases. The new research, published in *Nature Communications*, has revealed that a protein called ABHD11, found in the mitochondria (the cell's engines that power an immune response), plays a key role in regulating T-cell overactivity.

Researchers studied immune cells from the blood of individuals living with and without type 1 diabetes or rheumatoid arthritis and found that using a drug to stop the ABHD11 protein from working reduces inflammation by minimizing T-cell overactivity, limiting their production of inflammatory signals. The research also observed that blocking ABHD11 with the drug delayed the development of type 1 diabetes, offering hope for future therapies aimed at controlling autoimmune conditions. The team is hoping to extend its findings into the effects of blocking ABHD11 in other immune cell types with implications toward other autoimmune diseases.

New Research Uncovers Promising Target for Autoimmune Disease Treatment. Swansea University press release, Nov. 3, 2025. Accessed at www.swansea.ac.uk/press-office/news-events/news/2025/11/new-research-uncovers-promising-target-for-autoimmune-disease-treatment.php.

RESEARCH

High Levels of Oral Bacterium Linked to Increased Disability in MS Patients

A new study published in *Scientific Reports* found that periodontitis (severe gum disease) may worsen disability for people with multiple sclerosis (MS), a chronic autoimmune disease of the central nervous system.

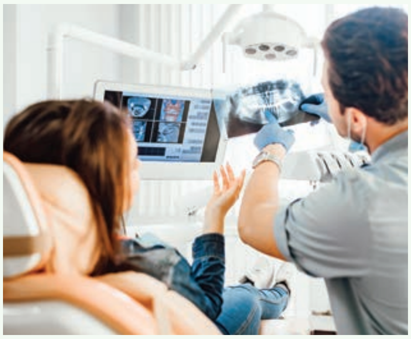
Periodontitis has been previously shown to contribute to central nervous system disorders through chronic inflammation. However, its role in MS has been unclear.

According to the new study, high levels of Fusobacterium nucleatum — a bacterium found in the mouth — were associated with about 10-fold higher odds of severe disability in MS patients.

"While the gut microbiome has been extensively investigated in [MS], the potential involvement of the oral microbiome has remained largely unexplored. Because the oral cavity is a major source of chronic inflammation and represents a potentially modifiable factor, clarifying its relationship with [MS] severity is important for understanding disease mechanisms and developing new preventive strategies," said Masahiro Nakamori, MD, PhD, an associate professor and lecturer at Hiroshima University Hospital.

The research team noted that nearly two-thirds (61.5 percent) of MS patients with a high relative abundance of Fusobacterium nucleatum fell into the moderate-to-severe disability range, compared with roughly one-fifth (18.6 percent) of those with milder disease. No such association was observed in patients with neuromyelitis optica spectrum disorder or myelin oligodendrocyte glycoprotein antibody-associated disease. MS patients with both Fusobacterium nucleatum and at least one other periodontal pathogen showed even higher disability.

"Fusobacterium nucleatum may act as a hidden 'bridge bacterium' — not only bridging bacterial communities in dental biofilms, but also potentially linking oral inflammation to neurological disability," said Dr. Nakamori.

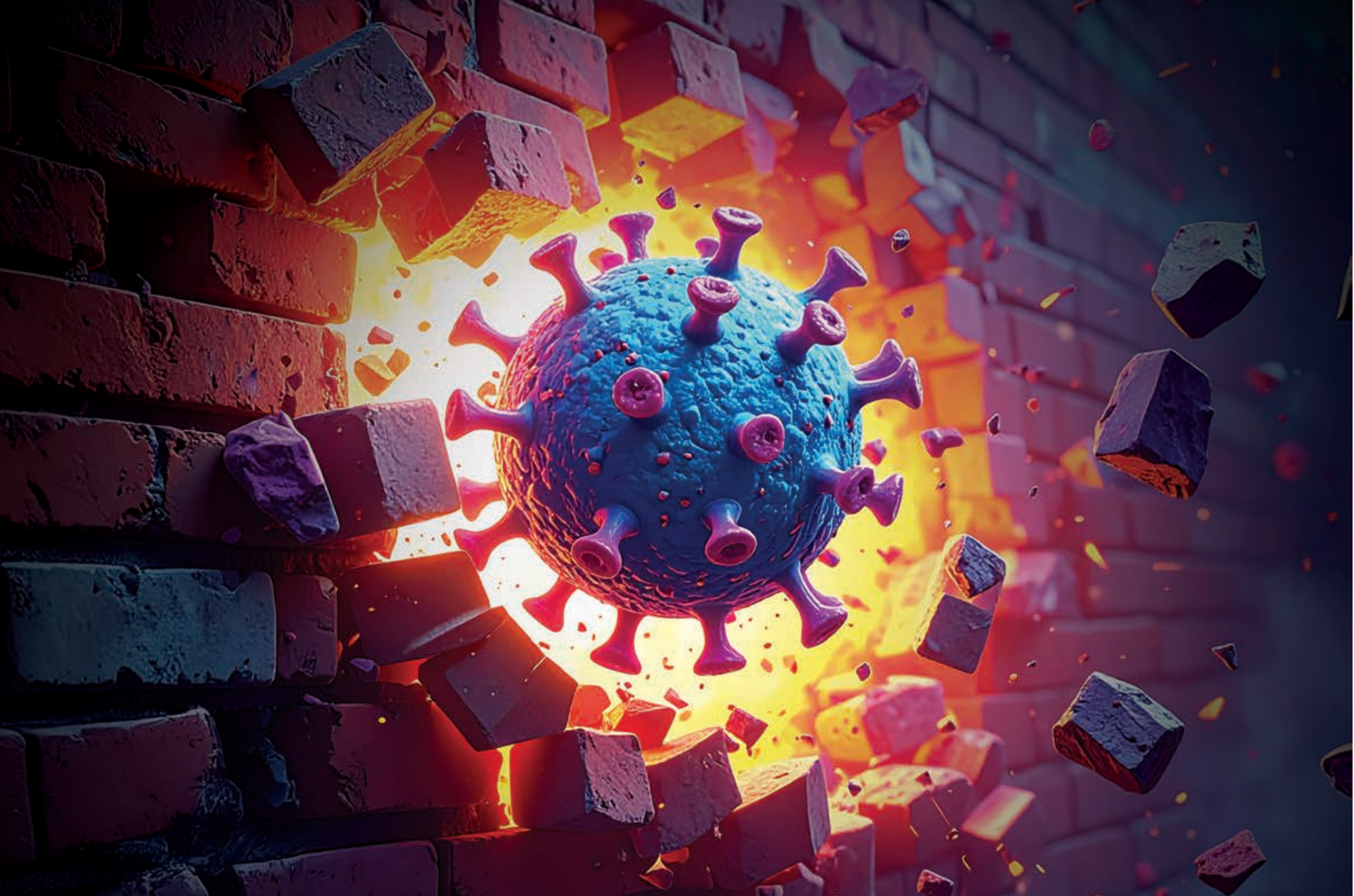


While the specific cause of MS remains unknown, viral infections, smoking, vitamin deficiencies and genetic predispositions are thought to be possible contributing factors. The team now hopes to conduct larger, multi-center studies to validate the association between oral bacteria and MS severity.

High Levels of Oral Bacterium Linked to Increased Disability in Multiple Sclerosis Patients, Finds Study. Indo-Asian News Service, Dec. 30, 2025. Accessed at www.ndtv.com/health/high-levels-of-oral-bacterium-linked-to-increased-disability-in-multiple-sclerosis-patients-finds-study-10092743.

Breakthrough Infections

What They Mean and How to Treat Them



Despite your best proactive efforts to stay healthy, pathogens can still make you sick — even when you're receiving immune globulin replacement therapy. Here's what to know and what to do if it happens to you.

By Kristi Van Winkle, RN, BSN, LNC

PRIMARY IMMUNODEFICIENCY (PI) is a hereditary condition that affects the body's ability to combat infections. People with PI do not produce enough antibodies to fight infections and are more likely to get sick or remain sick longer than a healthy person. Immune globulin (IG) replacement therapy consists of antibodies derived from donated human plasma and is used as a prophylactic treatment for infections in patients with PI.

IG therapy can be administered in one of two ways:

- Intravenous IG (IVIG) therapy is infused into a vein using a needle and intravenous tubing in a hospital, outpatient clinic, community clinic or home care setting, depending on the patient's individual needs. IVIG is generally administered at doses of 400-600 mg/kg of replacement immunoglobulins per month. But there is a "wear-off effect" that occurs near the end of the dosing cycle (known as "the trough"), right before the next dose is due, leaving the recipient susceptible to infection during this time.

- Subcutaneous IG (SCIG) therapy is administered by a small needle under the skin and can be given at home. SCIG may be an option if the patient has an adverse reaction to IVIG administration, poor venous access or if the patient's situation warrants it. SCIG is usually administered at lower doses, about 100 to 200 mg/kg, but is administered more frequently, typically every one to two weeks. SCIG achieves a steadier trough level than IVIG, but with lower peak levels. Because it requires smaller transfusion volumes and can be administered at home, this option generally leads to better patient compliance.[1]

The optimal administration method depends on an individual's unique medical needs, lifestyle and response to treatments. Both administration modes replace the missing antibodies in patients' blood, but neither stimulates patients' immune system to respond to infections. So, once PI patients start IG therapy, they will generally need to continue treatment for the rest of their lives.[2]

Yet even with IVIG or SCIG treatments, patients may still be vulnerable to breakthrough infections — infections that occur despite prophylactic treatments or vaccinations.[3,4] For example, if a person is fully vaccinated against a particular pathogen, such as SARS-CoV-2, the virus that causes COVID-19, but tests positive for that pathogen despite having been immunized against it, that person is considered to have a breakthrough infection. For PI patients receiving IG therapy, breakthrough infections develop despite IVIG or SCIG treatments.[5]

The ultimate goal of IG therapy is to maintain the highest quality of life for PI patients, prevent long-term organ damage and reduce the frequency and severity of breakthrough infections, not eliminate their risk.

Why Do Breakthrough Infections Happen After IVIG/SCIG Therapy?

During IVIG infusions, a healthcare provider administers the full dose of IVIG directly into the patient's bloodstream via an intravenous catheter. The full dose of antibodies enters the patient's circulatory system quickly and is metabolized or used by the body within a few weeks. IgG levels are at their highest (peak) immediately after the infusion and fall to their lowest (trough) just before the next dose of IVIG is due. This trough period, when IgG levels are at their lowest right before the next infusion, leaves patients more susceptible to infections.

SCIG may be more effective than IVIG at lowering the risk of breakthrough infections, though it cannot eliminate the possibility. SCIG is a lower dose of IG therapy given more frequently, providing more consistent IgG levels in the bloodstream, decreasing trough periods and limiting chances of breakthrough infections.[6]

Breakthrough infections are significant because they may indicate suboptimal immune protection, waning immunity or exposure to resistant organisms. Frequent or severe breakthrough infections may suggest IgG levels are inadequate and IG dosing needs adjustment, or that the donated antibodies are not effectively neutralizing a new infectious agent.

Early recognition and treatment of breakthrough infections is essential, particularly for PI patients. Decreased immune function may lead to faster deterioration in immunocompromised individuals than in immunocompetent individuals.

How Breakthrough Infections Are Treated

If a person receiving IVIG or SCIG develops a breakthrough infection, it is crucial to diagnose the condition promptly and begin treatment as soon as possible. That person should contact his or her healthcare provider (HCP) as quickly as possible after the first sign of new or worsening symptoms of an infection.

The HCP may run blood tests or scans to diagnose the breakthrough infection and prescribe appropriate treatment. He or she may then decide to increase the IG dose the patient is receiving, prescribe antibiotics or antiviral medications or recommend other immune-boosting therapies.

Laboratory Tests and Diagnostics

Identifying the causative organism is key to determining the optimal treatment.

The HCP will need to run tests to determine the cause of the breakthrough infection and the best way to treat it. Depending on symptoms, he or she may order blood tests, urine cultures, throat swabs or stool samples. In severe cases, the HCP may order a spinal tap to obtain spinal fluid for analysis. An X-ray, ultrasound, CT or MRI may also be ordered to further diagnose the condition. In some cases, such as a suspected fungal infection, a biopsy of the area may be needed.[7]

Increasing IG Doses

Increasing IG doses may be beneficial during breakthrough infections.

As mentioned before, every person is unique, and the amount of IG patients require will vary based on their diagnosis, symptoms, comorbidities and other lifestyle factors. Isolated infections, such as colds or ear infections, are not unusual even while on IG therapy. But an HCP may need to adjust patients' IG dosages if they are experiencing lingering symptoms such as a cough.

The typical starting dose range for IVIG is 400-600 mg/kg body weight.[8] Generally, a dosage within this range is adequate to protect immunodeficient patients from most infections. But if patients have comorbidities, such as chronic lung disease, they may need higher doses. Patients with comorbidities may benefit from IgG trough levels of 700 to 1,000 mg/dL to prevent infections, especially pneumonia.[9]

The goal of IVIG or SCIG is to reduce the frequency and severity of infections, not eliminate the risk.

A study published in the *Journal of Human Immunity* reported that optimal IgG levels vary by diagnosis, and an optimal dose is likely to begin at 800 mg/dl or higher. IgG treatments need to be individualized to achieve appropriate dosing and infusion intervals and attain optimal trough levels.[10] An HCP will adjust these doses based on trough levels and response to the treatment.

When patients develop an infection or experience persistent respiratory symptoms such as an ongoing cough or congestion, an HCP may consider prescribing a short-term course of high-dose IVIG to improve patients' chances of fighting off the pathogen. These higher IG doses can reduce the severity of bacterial infections and improve overall health.

Regular monitoring of IgG trough levels and infection frequency is crucial to guiding long-term therapy adjustments.

Prophylactic and On-Demand Antibiotics

An HCP may prescribe an antibiotic for a breakthrough infection.

Some PI patients, particularly those with common variable immunodeficiency, may be prescribed antibiotics prophylactically and given instructions for when to start them. For example, HCPs may advise patients to begin taking prophylactic oral antibiotics as soon as they start to experience symptoms of an infection, such as shortness of breath, cough or purulent sputum (thick, colored phlegm).[11] Patients may delay seeking medical attention or advice when they develop infection symptoms, thereby delaying antibiotic therapy. But, if they have antibiotics on hand "just in case" they develop symptoms, they may start taking them earlier, which can shorten the time they are sick.[5]

The challenge for HCPs is prescribing adequate antibiotic therapy without creating "superbugs," pathogens that are resistant to antibiotics and difficult to treat. For this reason, it is essential for patients to take antibiotics only as prescribed by an HCP and to finish the complete course of antibiotics as prescribed unless instructed to stop by an HCP.

Antibiotic resistance has become a public health threat in recent years. Scientists are working to develop new antibiotics to combat antibiotic-resistant pathogens, but the research and development process takes significant time to create the drugs and make them available.

To address the antibiotic resistance problem, HCPs may prescribe an older, less commonly prescribed antibiotic, but some of these have fallen out of use due to significant side effects. Another option being developed is called "phage therapy." Phage therapy involves viruses, called bacteriophages, that infect and kill specific bacteria in the body but do not infect people themselves. Phage therapy is not a new therapy. It was developed around the beginning of the 20th century, but the discovery of antibiotics pushed it into the background. The beauty of phage therapy is that bacteriophages target specific bacteria, while antibiotics kill a wide range of bacteria, including beneficial bacteria in the digestive tract. Phage therapy is still in the experimental stage of development and is not yet approved by the U.S. Food and Drug Administration.[12]

Early Antiviral Medications

Antivirals may be particularly important if patients have a higher risk for infections, such as those with PI, or if they live with or care for someone at higher risk for infection.

Antiviral medications may help reduce symptoms of respiratory viruses and shorten the time patients are sick if they have a virus such as the flu or COVID-19. As with antibiotics, starting antiviral medication early (soon after symptoms begin) may reduce the risk of some complications. If patients or a loved one has a higher risk of infection, they should contact their HCP as soon as possible after symptoms begin. Antivirals should be prescribed and administered as quickly as possible after symptoms appear. They are most effective if started within two days for flu and five to seven days for COVID-19.

Antivirals are available only by prescription and should not be taken for any infection other than the one for which they were prescribed. Antibiotics and antiviral medications do not work in the same way. Patients should not take antibiotics for a viral infection unless instructed to do so by a medical provider.

Lastly, patients should take all prescriptions strictly as prescribed by their HCP.[13]

Self-Care and Management

As with any infection, self-care is crucial.

Patients need to stay hydrated and rest when they start to feel "under the weather."

If they have, or suspect they have, a contagious infection that could spread to others, self-isolation is needed to reduce the risk of transmission. If patients must go out in public, they should wear a mask.

Patients should also wash their hands frequently.

Also, patients should talk to their doctor about alternative remedies that may help. Vitamin C, vitamin D, cranberry, ginseng, garlic and echinacea are touted as beneficial for certain infections, but definitive evidence for their healing abilities is limited, and some may interfere with medical conditions or prescribed medications patients are taking. This is why patients should always talk to their doctor before adding any supplement or alternative remedy to their health regimen.

Coordination of Care

Because PI patients often see a variety of medical specialists, such as immunologists, pulmonologists or cardiologists, effective management of breakthrough infections requires coordination among providers. Regular multidisciplinary reviews of medication dosing, vaccination status and infection control plans should be implemented to ensure all plans remain aligned.

Patients should consider keeping a diary or log to record symptoms, frequency and duration of breakthrough infections, along with their response to prescribed antibiotics or other therapies. This log could help HCPs evaluate the therapy's effectiveness and decide whether dose adjustments, additional prophylaxis or antibiotics are needed.

Proactive Protection

Research continues to improve IG formulations for better bioavailability and to refine IVIG and SCIG dosing strategies to reduce breakthrough infection rates further and improve the health and quality of life of people with PI. In the meantime, if a breakthrough infection occurs despite IVIG/SCIG therapy or vaccination, treatments are available.

Although IVIG/SCIG therapy cannot prevent all infections, breakthrough infections can be effectively treated with rapid recognition of symptoms, prompt diagnosis and appropriate treatment. Treatment may involve identifying the infection classification, promptly initiating appropriate antibiotics or antivirals and reassessing IG dosing to maintain optimal protection. Regular communication with the healthcare team is key to timely management and prevention of further episodes.

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KRISTI VAN WINKLE, RN, BSN, LSC, is a registered nurse and freelance health and medical writer. She has more than 15 years of experience as a nurse, working in a pediatric intensive care unit at the beginning of her career and then in an adult cardiac unit. She opened her writing business, Write Shift RN, in 2021.

Your Emergency Toolkit: Being Prepared with a Chronic Condition

Follow these simple steps to stay safe, stable and supported when systems fail.

By Surayyah Morris, PharmD

LIVING WITH a chronic condition means navigating a world that is not always predictable. Daily routines — taking medications, attending appointments, managing symptoms and practicing self-care — often depend on infrastructure working the way it is supposed to. Electricity powers things like medical devices and refrigerators. Transportation makes it possible to travel to pharmacies, schools, workplaces and healthcare providers. Telecommunication devices help you get in touch with emergency contacts or essential services when something goes wrong. When an unforeseen circumstance disrupts these systems, the impact of a power outage, road closure or a downed phone line can be much greater for someone managing a long-term health condition.

This is why having an emergency toolkit is not about fear, pessimism or expecting the worst. It is about preparation, self-advocacy and peace of mind. It is a way of recognizing that your health matters enough to protect, even when circumstances are chaotic or beyond your control. Preparedness is not panic; it is empowerment.

An emergency toolkit is a personalized plan and collection of resources that helps you protect your health during unexpected situations. Emergencies can include natural disasters or severe weather events such as storms, fires or floods, but also include power outages, evacuations, travel disruptions, sudden symptom flare-ups or unexpected trips to the emergency room. Even situations like getting sick while away from home or being unable to communicate clearly can quickly become overwhelming.

Preparing ahead of time allows you to respond calmly rather than react in crisis when an unexpected event happens. It reduces risk, helps prevent mistakes and ensures your health remains a priority even when everything else feels uncertain. Most importantly, it gives you a sense of control during moments when control may otherwise feel lost.

Use a Medical ID

At the heart of any emergency toolkit is information. Communication during emergencies can be challenging, particularly if your symptoms affect speech, movement, memory or cognitive clarity. Stress alone can make it hard to explain yourself, even without added health challenges. This is where medical identification (ID) becomes invaluable.

Medical ID tools quickly communicate essential information when you cannot. Options include:

- Medical alert bracelets or necklaces
- Wallet cards
- Phone lock-screen health information
- Medical ID apps

A medical ID can list your condition(s), allergies, medications and emergency contacts so first responders or caregivers can act appropriately. Some people also carry simple communication cards stating they have a chronic condition or may need extra time, assistance or accommodations.

Prepare a Personal Health Summary

A personal health summary is one of the most important components of your emergency toolkit. This document does not need to be long or complicated, but it should be clear, accurate and written in plain language so that anyone — first responders, teachers, caregivers or hospital staff — can understand it quickly. In a crisis, clear, accurate and accessible medical details can prevent confusion, delays and potentially dangerous misunderstandings. When you are stressed, unwell or unable to explain your medical needs, having your health information ready can speak for you. It builds on the information provided in your medical ID.

Your personal health summary should include:

- Full name
- Date of birth
- Chronic condition(s), with a brief explanation of them in everyday language
- Medications you take, including dosage and schedule
- Allergies or sensitivities (medications, foods, materials or environmental triggers)
- Medical devices you rely on
- Primary care doctor, specialist(s) and clinic information
- Emergency contact names and phone numbers

Keeping both a paper copy and a digital version is strongly recommended.

Digital tools play an important role in modern emergency planning. Storing medical information on your phone, backing up documents and saving important contacts can be incredibly helpful. However, technology is not guaranteed. Phones can run out of battery, networks can fail, devices can break and Internet access is not always available. A printed copy in your go-bag (which we'll discuss later), backpack or wallet ensures critical information is accessible even when digital tools are not.

Balancing digital tools with physical/tangible ones ensures critical information remains accessible no matter the circumstances. Redundancy is not excessive; it is smart.

Prioritize Medications

Medication preparedness is an essential part of emergency planning, especially for people with chronic conditions. Many individuals depend on daily or scheduled medications to remain stable. Even short interruptions can cause symptoms to worsen, trigger flare-ups or lead to medical emergencies.

An effective emergency toolkit accounts for this by including:

- A current list of medications, dosages and timing
- A backup supply of essential medications when possible and legally permitted
- Pharmacy contact information
- Prescription numbers, if available

Planning ahead for refills is also important. Knowing how to contact your pharmacy, healthcare provider or insurance company during disruptions can save valuable time and reduce stress. Some people choose to discuss emergency refill plans with their healthcare providers ahead of time so they know what to do if access becomes limited.

Proper storage of medications matters just as much as access. Medications should remain in clearly labeled containers and be protected from heat, moisture or light unless otherwise instructed. If a medication requires refrigeration or special handling, this should be noted in your health summary along with alternative plans in case of power outages.

Think About Technology

For individuals who rely on medical or assistive devices, emergency preparation goes beyond medication. Devices such as inhalers, glucose monitors, mobility aids, feeding equipment, hearing devices or communication tools often require accessories, maintenance or power.

Your emergency toolkit should include:

- Backup supplies (tubing, sensors, masks or attachments)
- Extra batteries or charging cables
- Written instructions or basic user guides
- Contact information for device providers or manufacturers

octagam® 10%

Immune Globulin
Intravenous (Human) 10%
Liquid Preparation

For the treatment of dermatomyositis (DM) in adults

Reach further with OCTAGAM 10%

The first and only IVIg FDA approved for DM

Not actual patient
IVIg=intravenous immunoglobulin.

INDICATIONS AND USAGE

OCTAGAM 10% is indicated for the treatment of chronic immune thrombocytopenic purpura (cITP) in adults and dermatomyositis (DM) in adults. For patients with cITP, it is used to rapidly increase the platelet count in the blood to help control or prevent bleeding. For patients with DM, it helps improve muscle function and skin rash.

OCTAGAM 10% is a liquid medication that contains Immunoglobulin G (IgG). OCTAGAM 10% is made from human plasma donated by healthy people. OCTAGAM 10% is given through the vein (intravenously) in a hospital, infusion center, or at home.

IMPORTANT SAFETY INFORMATION

- Do not use OCTAGAM 10% if you have had a severe allergic reaction to IgG or other blood products or have deficiencies of immunoglobulin A (IgA) with antibodies to IgA.
- OCTAGAM 10% can cause the following:
  - Blood clots in your heart, brain, lungs or other areas of your body
  - Kidney problems, or kidney failure
- Tell your healthcare provider (HCP) if you have an allergy to corn. OCTAGAM 10% contains a type of sugar that is made from corn.
- OCTAGAM 10% can cause the following serious side effects. Contact your HCP if you experience the following:
  - Swelling in your mouth or throat, hives/itching, breathing problems, wheezing, fainting, tightness in your chest, or dizziness. This could be a serious allergic reaction.
  - Decreased urination, swelling in your legs, sudden weight gain, or breathing problems, which could mean kidney failure
  - Pain and/or swelling of an arm or leg with warmth in the affected area, discoloration of an arm or leg, unexplained shortness of breath, chest pain or discomfort that worsens with deep breathing, unexplained rapid pulse, or numbness or weakness on one side of the body; these could be signs of a blood clot.
  - Yellow skin or eyes, dark-colored urine, fatigue, or increased heart rate, which could be signs of a blood problem.
  - Headache, stiff neck, drowsiness, fever, sensitivity to light, painful eye movements, or nausea and vomiting, which could mean an inflammation of the membranes covering your brain or spinal cord
  - Trouble breathing, chest pain, blue lips, arms or legs, and fever, which could be related to a lung problem. This typically occurs 1 to 6 hours following infusion.

OCTAGAM 10% helped patients achieve greater improvement in DM symptoms compared to placebo

In a clinical trial, 95 adults with dermatomyositis (DM) were split into two groups. Group 1 was given OCTAGAM 10% and Group 2 was given placebo. Patients in both treatment groups could continue taking their other medications while they were part of the trial. The clinical trial looked at how patients improved in DM muscle and skin symptoms. Researchers measured 3 levels of symptom improvement after 16 weeks: minimal, moderate, and major.[*]

[*] Symptoms were measured on a 100-point scale as measured by the Total Improvement Score (TIS), with 0 being worsening or no improvement and 100 being the most improvement. An improvement of at least 20 points was considered minimal; at least 40 points was considered moderate; and at least 60 points was considered major.

79%	68%	32%
At least minimal improvement vs 44% placebo (primary endpoint)	**At least moderate improvement** vs 23% placebo (secondary endpoint)	**Major improvement** vs 8% placebo (secondary endpoint)

Patients treated with OCTAGAM 10% saw **symptom improvement in 35 days**[†]

[†] Based on measuring median time to (at least) minimal improvement.

Most common drug-related side effects

In a clinical study, more than 5% of patients had the following side effects:

Headache: 42%; **Fever:** 19%; **Nausea:** 16%; **Vomiting:** 8%; **Chills:** 7%; **Musculoskeletal pain:** 7%; **Blood pressure increased:** 6%

$0 Eligible patients may pay as little as $0 with the OCTAGAM 10% Co-Pay Program[‡]

May reduce out-of-pocket costs by up to $12,500 per calendar year.

[‡] Terms and conditions apply. See full Terms and Conditions at **Octagam10CoPay.com**

Pfizer IGuide™ is committed to providing access solutions for patients prescribed OCTAGAM 10%.

Call 1-844-448-4337, Monday through Friday, 8 AM to 8 PM ET, or visit www.PfizerIGuide.com

Common side effects include headache, fever, nausea, vomiting, increased blood pressure, chills, musculoskeletal pain, dyspnea, infusion site reactions, and increased heart rate.

If you use a blood glucose monitor, check with your HCP to ensure that your monitor and test strips are acceptable to use while you are receiving OCTAGAM 10%.

These are not all of the possible side effects with OCTAGAM 10%. Tell your HCPs about any side effects that you have that cause concern or don't go away.

Patients should always ask their doctors for medical advice about adverse events.

You may report an adverse event related to Pfizer products by calling 1-800-438-1985 (US only). If you prefer, you may contact the U.S. Food and Drug Administration (FDA) directly. The FDA has established a reporting service known as MedWatch where healthcare professionals and consumers can report problems they suspect may be associated with the drugs and medical devices they prescribe, dispense, or use. Visit www.fda.gov/MedWatch or call 1-800-FDA-1088.

Talk to your doctor or visit OctagamInfo.com to learn more

Please see Brief Summary of full Prescribing Information on following page and full Prescribing Information, including complete BOXED WARNING, at OctagamInfo.com

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Immune Globulin
Intravenous (Human) 10%
Liquid Preparation

CONSUMER BRIEF SUMMARY

This brief summary highlights the most important information about OCTAGAM 10%. Please read it carefully before receiving OCTAGAM 10% and each time you have an infusion, as there may be new information. This brief summary does not take the place of talking with your healthcare provider (HCP) about your medical condition or your treatment. If you have any questions after reading this, ask your HCP. For more information, go to OctagamInfo.com/Octagam-10.

What is OCTAGAM 10%?

OCTAGAM 10% is a liquid medication that contains Immunoglobulin G (IgG). OCTAGAM 10% is used to treat chronic immune thrombocytopenic purpura (cITP) in adults and dermatomyositis (DM) in adults.

OCTAGAM 10% is made from human plasma donated by healthy people. For patients with cITP, it is used to rapidly increase the platelet count in the blood to help control or prevent bleeding. For patients with DM, it helps improve muscle function and skin rash.

OCTAGAM 10% is given through the vein (intravenously) in a hospital, infusion center, or at home by a trained HCP.

WARNING: THROMBOSIS, RENAL DYSFUNCTION, AND ACUTE RENAL FAILURE

- **Thrombosis may occur with immune globulin intravenous (IgIV) products, including OCTAGAM 10% liquid. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling central vascular catheters, hyperviscosity, and cardiovascular risk factors. Thrombosis may occur in the absence of known risk factors.**
- **Renal dysfunction, acute renal failure, osmotic nephrosis, and death may occur in predisposed patients who receive IgIV products, including OCTAGAM 10% liquid. Patients predisposed to renal dysfunction include those with a degree of pre-existing renal insufficiency, diabetes mellitus, age greater than 65, volume depletion, sepsis, paraproteinemia, or patients receiving known nephrotoxic drugs. Renal dysfunction and acute renal failure occur more commonly in patients receiving IgIV products containing sucrose. OCTAGAM 10% liquid does not contain sucrose.**
- **For patients at risk of thrombosis, renal dysfunction, or acute renal failure, administer OCTAGAM 10% liquid at the minimum dose and infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk for hyperviscosity.**

Who should NOT use OCTAGAM 10%?

Tell your HCP if you:

- Have had a severe allergic reaction to IgG or other blood products
- Have deficiencies of immunoglobulin A (IgA) with antibodies to IgA

What should I know before receiving OCTAGAM 10%?

OCTAGAM 10% can cause the following:

  - Blood clots in your heart, brain, lungs or other areas of your body
  - Kidney problems, or kidney failure
- Tell your HCP if you have an allergy to corn. OCTAGAM 10% contains a type of sugar that is made from corn.
- If you use a blood glucose monitor, check with your HCP to ensure that your monitor and test strips are acceptable to use while you are receiving OCTAGAM 10%

OCTAGAM 10% can cause the following serious side effects. Contact your HCP if you experience the following:

- Swelling in your mouth or throat, hives/itching, breathing problems, wheezing, fainting, tightness in your chest, or dizziness. This could be a serious allergic reaction.
- Decreased urination, swelling in your legs, sudden weight gain, or breathing problems, which could mean kidney failure.
- Pain and/or swelling of an arm or leg with warmth in the affected area, discoloration of an arm or leg, unexplained shortness of breath, chest pain or discomfort that worsens with deep breathing, unexplained rapid pulse, or numbness or weakness on one side of the body; these could be signs of a blood clot.
- Yellow skin or eyes, dark-colored urine, fatigue, or increased heart rate, which could be signs of a blood problem.
- Headache, stiff neck, drowsiness, fever, sensitivity to light, painful eye movements, or nausea and vomiting, which could mean an inflammation of the membranes covering your brain or spinal cord.
- Trouble breathing, chest pain, blue lips, arms or legs, and fever, which could be related to a lung problem. This typically occurs 1 to 6 hours following infusion.

What are the possible or reasonably likely side effects of OCTAGAM 10%?

Common side effects include headache, fever, nausea, vomiting, increased blood pressure, chills, musculoskeletal pain, dyspnea, infusion site reactions, and increased heart rate.

These are not all the possible side effects with OCTAGAM 10%. Tell your HCP about any side effects that you have that cause concern or do not go away. If you encounter any problems or experience side effects during or after the infusion, contact your HCP. When doing so, keep your therapy tracker with you to be able to give all necessary information.

Patients should always ask their doctors for medical advice about adverse events.

You may report an adverse event related to Pfizer products by calling 1-800-438-1985 (US only). If you prefer, you may contact the US Food and Drug Administration (FDA) directly. The FDA has established a reporting service known as MedWatch where healthcare professionals and consumers can report problems they suspect may be associated with the drugs and medical devices they prescribe, dispense, or use. Visit www.fda.gov/MedWatch or call 1-800-FDA-1088.

This brief summary is based on the OCTAGAM 10% Prescribing Information (March 2022).

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October 2023

Written instructions are especially important in the event someone other than you must use or troubleshoot your device. In stressful situations, even familiar technology can become confusing, so having simple explanations available can prevent mistakes.

If a device relies on electricity, planning for power outages is critical. Portable battery packs, power banks or identifying safe locations with backup power can make a significant difference. Thinking through these scenarios ahead of time turns uncertainty into preparedness.

Plan for Different Scenarios

Different emergencies require different responses. Thinking through possible scenarios ahead of time allows you to act rather than freeze. Power outages may affect medication storage or medical devices. Evacuations raise questions about transportation, accessibility and what to prioritize. Emergencies at school or work require clear communication with trusted adults, teachers or supervisors who understand your condition's needs.

Having tangible or easily communicable plans for these situations transforms uncertainty into actionable steps. When time is limited and stress is high, this reduces panic and supports safer decision-making.

Planning for routine disruptions means recognizing how stress, sensory overload or lack of rest may affect you. It also means identifying gentle coping strategies ahead of time.

Build a Go-Bag

A go-bag is a practical extension of your emergency toolkit. It is a small, easily accessible bag that you can grab quickly if you need to leave your home or move to a safer place in a hurry. The goal is not to pack everything you own, but to include essentials that support your health, safety and comfort.

Your go-bag might include:

- Your personal health summary
- Medications and medical supplies
- Copies of important documents
- Emergency contacts
- Snacks and water
- Assistive devices or accessories
- Comfort and regulation tools

5 Essential Go-Bag Supplies

Everyday needs: Include a toothbrush, cell phone, charger, glasses or whatever else you use daily.

First-aid kit: Include prescriptions and hand sanitizer in your first-aid kit.

Food and water: You need one gallon of water per person per day and a three-day supply of nonperishable food.

Important family documents: Store copies of important documents like your ID and bank account records in a waterproof bag.

Extra clothes: Pack for the weather in your area. Don't forget comfortable shoes.

Source: American Public Health Association. Emergency Preparedness. Accessed at www.apha.org/initiatives/get-ready/topics/emergency-preparedness

Items that support emotional regulation can be especially helpful during stressful situations. These may include noise-canceling headphones, familiar music, fidget tools, sensory-friendly items or calming objects. While these items may seem small, they can help reduce overwhelm and make difficult situations more manageable. Keep your go-bag lightweight, organized and stored in a consistent, easy-to-reach place. Review it periodically to ensure everything inside is still relevant and in good condition.

Food, Water — and Allergies

Preparing shelf-stable, safe food options and ensuring access to clean water helps maintain stability during emergencies. Disruptions in regular routines for meals can have repercussions on medicines and symptoms. Having food at the ready can help.

Food and medication allergies are especially important to consider in the event of an emergency when your "safe" food and medications aren't readily available. Being caught without safe food to eat or emergency medication to treat allergic reactions (such as epinephrine) can make a stressful situation worse. Prepare for this contingency as best as you can by including shelf-stable food in your emergency kit. Communicate significant dietary needs (such as a gluten-free diet due to celiac disease) and food or medication allergies in your health summary as well so others understand the severity of your needs.

A Note About Emotional and Mental Health

Emotional and mental health support is an often-overlooked, but vital part of emergency preparedness. Emergencies can increase anxiety, fear and overwhelm, which can intensify physical symptoms. Preparing for emotional needs is not a weakness; it is a form of resilience.

Your emergency toolkit can include things to help manage mental health such as:

- Grounding or breathing techniques
- Familiar music or calming sounds
- Written reminders of coping strategies
- Journaling tools or coloring books
- Games or phone apps
- Contact information for supportive people

These tools help restore a sense of control and stability during difficult moments.

Build a Support Network

No emergency plan works in isolation. Building a support network strengthens your toolkit and ensures you are not facing challenges alone. Trusted people — parents, guardians, friends, teachers, coaches or coworkers — should know about your condition, where your emergency information is kept and how they can help when needed. Clear communication ahead of time reduces confusion and allows others to support you effectively. Preparedness is not about doing everything alone; it is about knowing when and how to ask for help.

An Ongoing Act of Self-Care

An emergency toolkit is not a one-time project. As your health, medications or living situation change, your toolkit should change too. Reviewing it every six months or once a year (you'd be surprised how fast six months comes around!) helps keep information accurate and supplies useful. This habit turns preparedness into an ongoing act of self-care rather than a reaction to fear.

> **Preparedness is not panic;**
> **it is empowerment.**

For teens and young people with chronic conditions, building an emergency toolkit is also an opportunity to develop independence. While adults and caregivers play an important role, understanding their own needs and participating in planning builds confidence and self-advocacy skills. Preparedness is about having a voice, not carrying responsibility alone.

Final Thoughts

Ultimately, being prepared does not mean expecting something bad to happen. It means recognizing your worth and ensuring your health is protected in all circumstances. Living with a chronic condition already requires strength, adaptability and awareness. An emergency toolkit organizes that strength into a form that supports you when the unexpected occurs. IG

SURAYYAH MORRIS, PharmD, is an IG patient from Central Florida. As a long-term care and medication therapy management pharmacist, she enjoys supporting patients in managing chronic conditions to help them find balance and improve quality of life.

Caregiving for Chronic Illness:

Practical Strategies for Comfort, Compassion and Companionship

Giving a sick loved one the dignity of a comfortable, connected life is rewarding — and exhausting. These tips can ease the burden and help cultivate a life that works for you both.

By Rachel Colletta, BSN, CRNI, IgCN

CARING FOR someone with a chronic illness is not a race to the finish; it's a long, evolving journey marked by resilience, adaptability and deep connection. Supporting a loved one through chronic illness means embracing an ongoing process — one that calls for patience, flexibility and unwavering emotional support.

Unlike acute medical events with defined beginnings and ends, chronic conditions unfold over months and years, reshaping routines, expectations and identities. Caregiving in this context is not only about tasks and treatments; it's about building a life that accommodates shifting symptoms while preserving dignity, agency and connection.

Millions of families face this reality every day. Many caregivers are spouses, partners or adult children who begin by "helping out" and gradually transition into coordinating medications, tracking appointments, navigating insurance, advocating in health systems and providing hands-on support with activities of daily living. Over time, caregivers become vital interpreters of the patient's lived experience — recognizing subtle cues, anticipating needs and shaping the home environment to make daily life safer and more manageable.

To sustain health and hope across the timeline of chronic illness, three practical guideposts — comfort, compassion and companionship (the "3 Cs") — anchor the caregiving relationship. Comfort reduces the physical burden of disease. Compassion validates the emotional complexity of living with persistent symptoms. Companionship protects connection and meaning even when energy is limited. Together, the 3 Cs create a humane, sustainable framework that helps patients and caregivers not merely cope, but live.

Comfort: Easing the Physical Burden

Comfort is more than symptom relief; it's the intentional design of routines and environments that align with the realities of chronic disease. The aim is to reduce friction, conserve energy and maintain independence where possible — without overmedicalizing home life or diminishing the patient's sense of self.

Design a supportive home environment. Because most chronic care occurs at home, the living space becomes a therapeutic ally. Start with small, high-impact adjustments:

- Access and reach: Place frequently used items (medications, water, phone, lotions, assistive tools) at waist height to minimize bending and stretching. Use open shelving or clear bins for easy visibility.
- Mobility and safety: Install grab bars in bathrooms, non-slip mats in showers and night lights along pathways. Consider supportive seating with firm arms for easier transfers and cushions that reduce pressure points.
- Temperature and sensory comfort: Keep a fan, cooling towel, heating pad or weighted blanket accessible. Adjust lighting to reduce glare and eyestrain — especially helpful on days when fatigue or cognitive fog is high.
- Rest-ready spaces: Create quiet, calming areas for recuperation: a comfortable chair, a pillow wedge, a warm and comfortable blanket and a tidy side table for essentials. Rest areas distributed across the home can encourage strategic pauses without derailing the day.

Respect energy limits: pacing and prioritization. Fatigue is one of the most common and challenging symptoms in chronic illness. Developing strategies for when and how to engage in daily tasks, attend appointments and participate in family gatherings can significantly enhance enjoyment and reduce the stress associated with these activities.

Pacing, which means intentionally planning and balancing activities with periods of rest, helps to manage fatigue by preventing overexertion and allowing for more sustainable energy throughout the day. Energy behaves like a finite budget — once overspent, "recovery fees" appear in the form of frustration and days lost to exhaustion.

Pacing strategies protect this budget:

- Plan activities a week in advance: Mapping out appointments, errands and social plans helps distribute energy more evenly and prevents last-minute overload. This proactive approach allows for adjustments and ensures the energy budget is balanced across busy and lighter days.
- Prioritize essentials: Identify "must-do" tasks versus "nice-to-do" tasks. Offload or postpone the latter, particularly during flare-ups or treatment transitions.
- Break tasks into segments: Clean one countertop, not the whole kitchen. Fold laundry in short bursts. Use timers to cap effort at 10 to 20 minutes, followed by rest.
- Alternate energy types: Rotate physical tasks (e.g., tidying) with cognitive ones (e.g., paying a bill) to avoid taxing one system continuously.
- Plan around natural rhythms: Many patients have a mid-morning energy window. Schedule showers, appointments or errands during this time, keep afternoons lighter and protect evenings for decompression.
- Build "buffers": Always leave 20 to 30 percent energy unspent to avoid the post-exertional "crash."

Compassion is presence with dignity.

In addition to daily pacing, consider how to approach larger activities such as family gatherings or outings. When possible, schedule these events on days when a rest day is available before or after, allowing for preparation and recovery time. Communicate plans clearly with loved ones so everyone understands the need for flexibility and possible last-minute adjustments. By thoughtfully spacing out major activities and building in recovery time, patients can

Table 1: Comfort

Comfort Concerns	Helpful Strategies
Morning pain and stiffness	• Warm showers • Heating pads • Gentle stretches • Delayed scheduling
Limited mobility	• Grab bars • Non-slip mats • Supportive chairs • Reachable storage
Temperature sensitivity	• Fans/cooling towels • Heating pads/blankets • Layered clothing
Orthostatic symptoms	• Slow position changes • Hydration • Compression garments if appropriate
Sleep disruption	• Comfort positioning • Consistent bedtime routine • Reduced evening stimuli

participate more fully without overwhelming their limited energy reserves.

Caregivers enhance pacing by modeling restraint — resisting the urge to "make up for lost time" on a good day — because boom-and-bust cycles erode confidence and lengthen recovery time.

Layer symptom relief. Chronic illness frequently involves multiple interacting symptoms — pain, stiffness, neuropathy, nausea, dizziness, cognitive fog and sleep disruption. Layered strategies help:

- Pain and stiffness: Use heat for muscle tension; cold for inflamed joints. Gentle mobility (Tai chi, stretching, aquatic therapy) supports range of motion without overloading sore tissue. Consider comfort positioning with wedges, lumbar rolls and pressure-relieving cushions to improve sleep and morning function.
- Neuropathic discomfort: TENS units, gentle massage or mindfulness-based practices can complement medications. Proper footwear with support and seamless socks reduces irritants.
- Digestive comfort: Opt for small, frequent meals. Bland, room-temperature foods are often easier on "nausea days." Keep ginger tea, peppermint oil (for external use) or prescribed antiemetics readily accessible. Use raised head positioning after meals to reduce reflux.
- Cognitive fog: Simplify routines. Use pill organizers and alarms, color-coded calendars and checklists. Reduce sensory clutter in workspaces. Encourage "single-tasking" and short cognitive blocks with clear stopping points.

Care routines that preserve autonomy. Autonomy protects identity. Work together as a team to co-design routines:

- Collaborative planning: Ask, "What feels doable today?" Create a shared daily plan with options and contingency paths.
- Control over care: Offer choices — preferred timing for medications, order of tasks, the playlist during infusion days or the flavor of oral supplements.
- Support for alone time: Recognize the patient's need for solitude by offering opportunities to spend time alone. It is equally important for the caregiver to have time alone to rest, recharge and maintain their own well-being. Regular breaks for both the patient and caregiver help prevent burnout and foster a healthier caregiving relationship.

When comfort is individualized and autonomy preserved, patients experience caregiving as a partnership rather than control.

See Table 1 for a list of practical strategies for easing physical discomfort.

Compassion: Honoring the Emotional Landscape

Compassion is the courage to sit with the realities of chronic illness — losses, fears, frustrations — without rushing to solutions or minimizing pain. It is presence with dignity.

Name the losses. Chronic illness alters life trajectories. Patients may grieve changed abilities, role transitions, social disruptions and future uncertainty. Losses are not linear; they resurface during flares, new diagnoses or treatment changes. Compassionate responses validate and normalize these cycles: "It makes sense that this feels heavy today. You've had to give up so much."

Practice validation over fixing. Encouragement like "Stay positive" or "At least it's not worse" can come across as dismissive. Compassion favors validation — reflective listening, permission for emotion and non-urgent presence. Small rituals of care convey steadiness more than speeches do.

Support caregiver emotions. Caregivers experience their own grief over the life once imagined, changing partnership dynamics and the persistent vigilance required. Burnout signals include irritability, numbing, resentment and withdrawal. These are signals, not moral failures.

Sustaining strategies: Set limits, take guilt-free breaks, seek peer support, engage professional help when needed, and protect identity through hobbies, friendships and health maintenance. Compassion given to oneself is essential for long-term caregiving capacity.

See Table 2 for suggested supportive responses for emotional challenges.

Companionship: Protecting Connection and Meaning

Chronic illness narrows the world — but it doesn't have to eliminate connection or joy. Companionship is the intentional preservation of a relationship within the

Table 2: Compassion

Emotional Challenges	Supportive Responses
Grief over lost abilities	• Validate feelings • Name the loss • Avoid toxic positivity
Fear of progression	• Offer presence • Clarify information • Reduce uncertainty when possible
Guilt about burdening others	• Normalize feelings • Share care • Reinforce inherent worth
Caregiver burnout	• Plan respite • Set boundaries • Seek therapy/support groups

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Count the reasons
to ask your care team about cutaquig

1
hour or less to
complete infusion[*]

2
or fewer
infusion sites[†‡]

3
flexible dosing
schedule options[§]

Not an actual patient.

[*] The estimated infusion duration for a 13 g (78 mL) weekly dose is approximately 45 minutes in an adult patient using 2 infusion sites, if tolerated, not including setup time.
[†] Depending on your dose and dosing schedule selected.
[‡] Most infusions only need 2 or fewer infusion sites.
[§] Every-other-week, weekly, or frequent dosing (2-7 times a week).

INDICATIONS AND USAGE

CUTAQUIG (Immune Globulin Subcutaneous [Human] - hipp) is a 16.5% immune globulin solution for subcutaneous infusion indicated for treatment of primary humoral immunodeficiency (PI) in adults and pediatric patients 2 years of age and older.

There are many forms of PI. Certain types of PI are associated with low immunoglobulin G (IgG), which are proteins that help fight infection.

CUTAQUIG is a liquid medicine for infusion that contains immunoglobulin G (IgG), which are proteins that help fight infection. It is made from human plasma that is donated by healthy people and contains antibodies that replace the missing antibodies in patients with PI.

CUTAQUIG is given under the skin (subcutaneous). Most of the time, infusions under the skin are given at home by self-infusion or by a caregiver. Only use CUTAQUIG by yourself after you have been instructed on use by a healthcare provider (HCP).

IMPORTANT SAFETY INFORMATION

WARNING: THROMBOSIS

See full Prescribing Information for complete BOXED WARNING

- **Thrombosis may occur with immune globulin products, including CUTAQUIG. Risk factors may include advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling vascular catheters, hyperviscosity, and cardiovascular risk factors.**
- **For patients at risk of thrombosis, administer CUTAQUIG at the minimum dose and infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk of hyperviscosity.**

What is the most important information I need to know about CUTAQUIG?

CUTAQUIG can cause the following serious reactions:

- Severe allergic reactions causing difficulty in breathing or skin rashes
- Blood clots in the heart, brain, lungs, or elsewhere in the body
- Severe headache, drowsiness, fever, painful eye movements, or nausea and vomiting
- Decreased kidney function or kidney failure
- Dark colored urine, swelling, fatigue, or difficulty breathing

CUTAQUIG is made from human blood. The risk of transmission of infectious agents, including viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent, and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent cannot be completely eliminated.

Scan to visit **CutaquigInfo.com** to learn more.

What should I know while taking CUTAQUIG?

- CUTAQUIG can make vaccines (like measles/mumps/rubella or chickenpox vaccines) not work as well for you. Before you get any vaccines, tell your HCP that you take CUTAQUIG
- Tell your HCP if you are pregnant, or plan to become pregnant, or if you are nursing

CUTAQUIG can cause serious side effects. If any of the following problems occur after starting CUTAQUIG, contact your HCP or call emergency services. If any of the following problems occur during CUTAQUIG infusion, stop the infusion immediately and contact your HCP or call emergency services:

- Hives, swelling in the mouth or throat, itching, trouble breathing, wheezing, fainting, or dizziness. These could be signs of a serious allergic reaction
- Bad headache with nausea, vomiting, stiff neck, fever, and sensitivity to light. These could be signs of irritation and swelling of the lining around your brain
- Reduced urination, sudden weight gain, or swelling in your legs. These could be signs of a kidney problem
- Pain, swelling, warmth, redness, or a lump in your legs or arms. These could be signs of a blood clot
- Brown or red urine, fast heart rate, yellow skin or eyes. These could be signs of a liver or blood problem
- Chest pain or trouble breathing, or blue lips or extremities. These could be signs of a serious heart or lung problem
- Fever over 100°F. This could be a sign of an infection

Ask your HCP whether you should have rescue medications available, such as antihistamines or epinephrine.

What are the possible or reasonably likely side effects of CUTAQUIG?

The most common side effects of CUTAQUIG are:

- Infusion site reactions (including but not limited to redness, swelling, itching, fluid in tissue, pain, mass, bruising)
- Headache
- Elevated body temperature

One or more of the following possible side effects may occur at the site of infusion; these may go away within a few hours and are less likely after the first few infusions:

- Mild or moderate pain
- Redness
- Itching

These are not all the possible side effects. Talk to your HCP about any side effect that bothers you or that does not go away.

Patients should always ask their doctors for medical advice about adverse events.

You may report an adverse event related to Pfizer products by calling 1-800-438-1985 (US only). If you prefer, you may contact the US Food and Drug Administration (FDA) directly. The FDA has established a reporting service known as MedWatch where healthcare professionals and consumers can report problems they suspect may be associated with the drugs and medical devices they prescribe, dispense, or use. Visit www.fda.gov/MedWatch or call 1-800-FDA-1088.

CUTAQUIG® is a registered trademark of Octapharma AG.

Please see brief summary of Full Prescribing Information on following page and Full Prescribing Information, including complete BOXED WARNING and Patient Information and Instructions for Use, at CutaquigInfo.com.

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CONSUMER BRIEF SUMMARY

(CUTAQUIG: *cute-ah-quig*)

This brief summary highlights the most important information about CUTAQUIG. Please read it carefully before using CUTAQUIG and each time you get a refill, as there may be new information. This Patient Information does not take the place of talking with your healthcare provider about your medical condition or your treatment. If you have any questions after reading this, ask your healthcare provider. For more information, go to www.CutaquigInfo.com.

What is CUTAQUIG?

CUTAQUIG is a ready-to-use liquid solution of immunoglobulin G (IgG), also called antibodies, which protects the body against infection. CUTAQUIG is used to treat adult patients and pediatric patients 2 years of age and older with primary humoral immunodeficiency (PI).

There are many forms of PI. The most common types of PI result in an inability to make a very important type of protein called antibodies, which help the body fight off infections from bacteria or viruses. Regular administration of CUTAQUIG has been demonstrated to help your body to fight bacteria and viruses that cause infections. CUTAQUIG is made from human plasma that is donated by healthy people. CUTAQUIG contains antibodies collected from these healthy people; these antibodies replace the missing antibodies in patients with PI.

WARNING: THROMBOSIS

See full Prescribing Information for complete BOXED WARNING

- **Thrombosis may occur with immune globulin products, including CUTAQUIG. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling central vascular catheters, hyperviscosity, and cardiovascular risk factors.**
- **For patients at risk of thrombosis, administer CUTAQUIG at the minimum dose and infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk of hyperviscosity.**

Who should NOT use CUTAQUIG?

Do not use CUTAQUIG if you have ever had a severe allergic reaction to immune globulin or other blood products.

Tell your healthcare provider if you:

- Ever had any severe reaction to other immune globulin medicines
- Were told that you have a condition called IgA deficiency
- Have a history of heart or blood vessel disease
- Have had blood clots or thick blood
- Have been immobile for some time

CUTAQUIG can cause serious side effects. If any of the following problems occur after starting CUTAQUIG, contact your HCP or call emergency services. If any of the following problems occur during CUTAQUIG infusion, stop the infusion immediately and contact your HCP or call emergency services:

- Hives, swelling in the mouth or throat, itching, trouble breathing, wheezing, fainting, or dizziness. These could be signs of a serious allergic reaction
- Bad headache with nausea, vomiting, stiff neck, fever, and sensitivity to light. These could be signs of irritation and swelling of the lining around your brain
- Reduced urination, sudden weight gain, or swelling in your legs. These could be signs of a kidney problem
- Pain, swelling, warmth, redness, or a lump in your legs or arms. These could be signs of a blood clot
- Brown or red urine, fast heart rate, yellow skin or eyes. These could be signs of a liver or blood problem
- Chest pain or trouble breathing, or blue lips or extremities. These could be signs of a serious heart or lung problem
- Fever over 100°F. This could be a sign of an infection

CUTAQUIG is made from human blood. The risk of transmission of infectious agents, including viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent, and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent cannot be completely eliminated.

What should I tell my healthcare provider before using CUTAQUIG?

Talk to your healthcare provider about any medical conditions that you have or have had.

Tell your healthcare provider:

- That you are taking CUTAQUIG before you get a vaccination, as vaccines may not work while you are taking CUTAQUIG.
- About all of the prescription and non-prescription medicines you take, including over-the-counter medicines, dietary supplements, or herbal medicines.
- If you are pregnant, plan to get pregnant, or if you are nursing because CUTAQUIG might not be right for you.
- If you have diabetes. If you need to do glucose testing, your healthcare provider may tell you to use a different way to monitor your blood sugar levels on the day that you receive a CUTAQUIG infusion. Some types of blood glucose testing systems (glucometers) can falsely interpret the maltose contained in CUTAQUIG as glucose. If you are uncertain, ask your healthcare provider which glucose testing system you can use while using CUTAQUIG.

The most common side effects that may occur with CUTAQUIG are:

- Infusion site reactions (including but not limited to redness, swelling, itching, fluid in tissue, pain, mass, bruising)
- Headache
- Elevated body temperature

One or more of the following possible side effects may occur at the site of infusion; these may go away within a few hours and are less likely after the first few infusions:

- Mild or moderate pain
- Redness
- Itching

These are not all the possible side effects. Talk to your HCP about any side effect that bothers you or that does not go away. If you encounter any problems or experience side effects during or after the infusion, contact your healthcare provider. When doing so, keep your treatment diary or logbook with you to be able to give all necessary information.

Patients should always ask their doctors for medical advice about adverse events.

You may report an adverse event related to Pfizer products by calling 1-800-438-1985 (US only). If you prefer, you may contact the US Food and Drug Administration (FDA) directly. The FDA has established a reporting service known as MedWatch where healthcare professionals and consumers can report problems they suspect may be associated with the drugs and medical devices they prescribe, dispense, or use. Visit www.fda.gov/MedWatch or call 1-800-FDA-1088.

This brief summary is based on the CUTAQUIG Prescribing Information (October 2021).

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March 2022

constraints of disease.

Redesign social life. Traditional activities may be too taxing, but connection is adaptable. Choose low-energy formats (short home visits, brief video calls, voice messages), parallel presence (reading or watching a show together), flexible planning and micro-moments of joy anchored in daily rituals.

Online and community supports. Condition-specific online communities provide lived-experience knowledge for patients and caregivers. Local resources — faith communities, neighborhood groups, volunteer networks — often welcome opportunities to help when needs are clearly communicated and right-sized.

Purpose within limits. Chronic illness does not cancel purpose; it reshapes it. Meaning may come through creative expression, nurturing plants or pets, learning and sharing, and advocacy or mentorship. Celebrations may be smaller or spread across several days; intention and acknowledgement matter more than scale.

See Table 3 for ideas to help overcome barriers to connection.

Table 3: Companionship

Connection Barriers	Adaptable Approaches
Low energy	• Short visits • Video calls • Brief shared activities
Social withdrawal	• Low-pressure invitations • Online communities • Check-ins by text
Limited mobility	• Home-based gatherings • Adaptive hobbies • Accessible spaces
Unpredictable symptoms	• Flexible plans • Tentative RSVPs • Guilt-free cancellations

Putting the 3 Cs Into Practice: A Daily Blueprint

The 3 Cs are interdependent. Comfort makes emotional presence possible; compassion encourages trust and honest communication; companionship sustains motivation and hope. A sample day weaves them together with morning comfort routines, mid-day planning that respects energy, afternoon connection, evening validation and sleep-supportive setups. The goal is not perfection, but consistency.

> **Caregiving is about building a life that accommodates shifting symptoms while preserving dignity, agency and connection.**

Caregiving for chronic illness asks much of patients and families — adaptability, patience, creativity and courage. The 3 Cs — comfort, compassion and companionship — offer a practical, human framework to meet that ask. Comfort reduces physical barriers and conserves energy. Compassion honors the emotional terrain and nurtures trust. Companionship protects connection and meaning when life narrows.

This approach does not cure chronic illness, but it does promote dignity: a daily life shaped by understanding, flexibility and care. For the millions walking this path, the 3 Cs transform caregiving from a series of tasks into the work of love — made sustainable, shared and deeply human.

Resources

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RACHEL COLLETTA, BSN, CRNI, IgCN, is director of education at the Immunoglobulin National Society.

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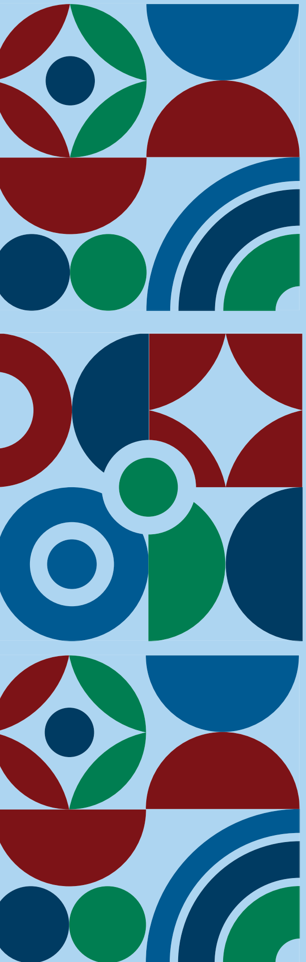
Take the self-assessment to find out if your symptoms could point to a primary immunodeficiency (PI). It's an informative way to gather insights that you can discuss with your healthcare provider.

idf.primaryimmune.org/immunetest



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Whether you've been recently diagnosed, have been living with a primary immunodeficiency (PI) for years, or just think you might have a PI, the Immune Deficiency Foundation is here to help.

While PI has no cure, there are lifesaving treatments available that can improve your quality of life. Our programs are meant to connect, engage, and empower families to live longer, stronger, healthier lives.

SCAN ME

Immune Deficiency Foundation

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Daily Exercises Seniors Can Perform at Home

These seven easy and safe movements can help you stay active, strong and independent.

By Amy Scanlin, MS

MOVEMENT CAN be the key to a life well lived. It increases longevity, improves health and contributes to happiness and a sense of fulfillment — even for those advancing in years!

In fact, older adults are throwing away outdated notions of "ageism" and embracing "ableism" instead, overcoming perceived negative barriers of what vibrant aging should look like by pursuing purposeful and enjoyable exercise that keeps them active and engaged. They are increasingly embracing this special stage of life with a positive, can-do attitude.

Why Get Active as You Age?

Physical activity is beneficial to your health no matter your age. However, it's of particular concern as you age due to an increased fall risk. The Centers for Disease Control and Prevention states that each year more than 25 percent of adults age 65 years and older fall. These falls lead to three million emergency room visits and, in some cases, life-altering outcomes that can limit one's mobility. But, staying active can help reduce your risk of falls.

However, the fear of falling also prevents many seniors from exercising at all. Unfortunately, this fear can prompt devastating consequences. Reduced physical activity can increase blood pressure and decrease muscle strength and flexibility, to name a few. It can also prevent one from leaving the house, leading to social isolation. Ironically, avoiding physical activity can actually lead to an increased fall risk. So, staying active in a safe manner is the name of the game.

Focusing on movements that improve balance and strength can help reduce fall risk. When those movements simulate everyday activities, all the better. For instance, sit to stand exercises simulate sitting down and standing from a chair. Arm pushes can help to gain strength so you can better push and pull your body weight. Even balancing movements are important to preventing falls. Taken together, these movements create a comprehensive exercise routine that is both fun to do and beneficial for you.

Let's Get Started!

Of course, the first step before embarking on a new activity is to see your doctor to confirm it is safe to do so.

You may also want to initially work with a personal trainer who specializes in the unique needs of older adults.

Once you get the green light, try the following exercises. They do not require special equipment beyond a sturdy arm chair without wheels, a counter, a wall free from clutter and comfortable, sturdy shoes (like sneakers). Modifications are also offered that make the exercises a little easier or a little harder.

Marching in Place

This exercise simulates walking, challenges your balance and gets your heart pumping! It's a great start for your exercise program. Turn on your favorite music and try marching for one song. If you have the energy, march for two songs!

- *How to do it*: Find clear floor space that is not slippery and free from throw rugs. Stand tall, tighten your torso and start marching!
- *Make it easier*: If you need a little bit of balance assistance, try marching while standing next to a sturdy chair so you can reach out and use it to steady yourself as needed. If marching while standing is too challenging, sit down in a sturdy chair and march those feet on the floor. Don't forget to keep your torso tall and tighten your stomach muscles!
- *Make it harder*: Pump your arms while marching. Bend your elbows to 90 degrees and turn your palms down to face your knees. Try lifting your knees high as if you are trying to touch your palms.
- *When to stop*: Neuropathy, or tingling and numbness in your feet, can make activities like marching and walking difficult. Also, if you feel discomfort in your hips, knees, ankles or feet, check with your doctor or trainer.

Balance Exercises

Balance exercises help your body recover from inadvertent trips or slips, allowing you an opportunity to regain balance and hopefully catch yourself. Improvement takes practice, just like anything else. Try holding this balance exercise for 10 seconds and work your way up to 30 seconds.

- *How to do it*: First, make sure you have a sturdy chair or counter next to you, or even a friend whose supportive hand is close by if needed. Stand on a surface that is free from slippery throw rugs, and keep your feet directly under your hips and knees. Shift your weight slightly to one leg and bend the opposite knee, lifting your foot off the floor. If you feel unsteady and need to place a hand on that supportive chair back, do so!
- *Make it easier*: If balancing is difficult for you, don't worry — balancing is hard! To make it easier, make good use of that supportive chair back or counter and hold on. As you feel stronger, let go just for a second or two to see how it feels. You may also try lifting only your heel, leaving your toe on the ground for support.
- *Make it harder*: There are lots of ways to further challenge your balance, but don't try all of these at once. Try standing in your bare feet versus sneakers, closing your eyes while balancing or holding the balance for a little longer. Whatever you try, keep that support close by so you can take hold of it when you need to.

Write the Alphabet

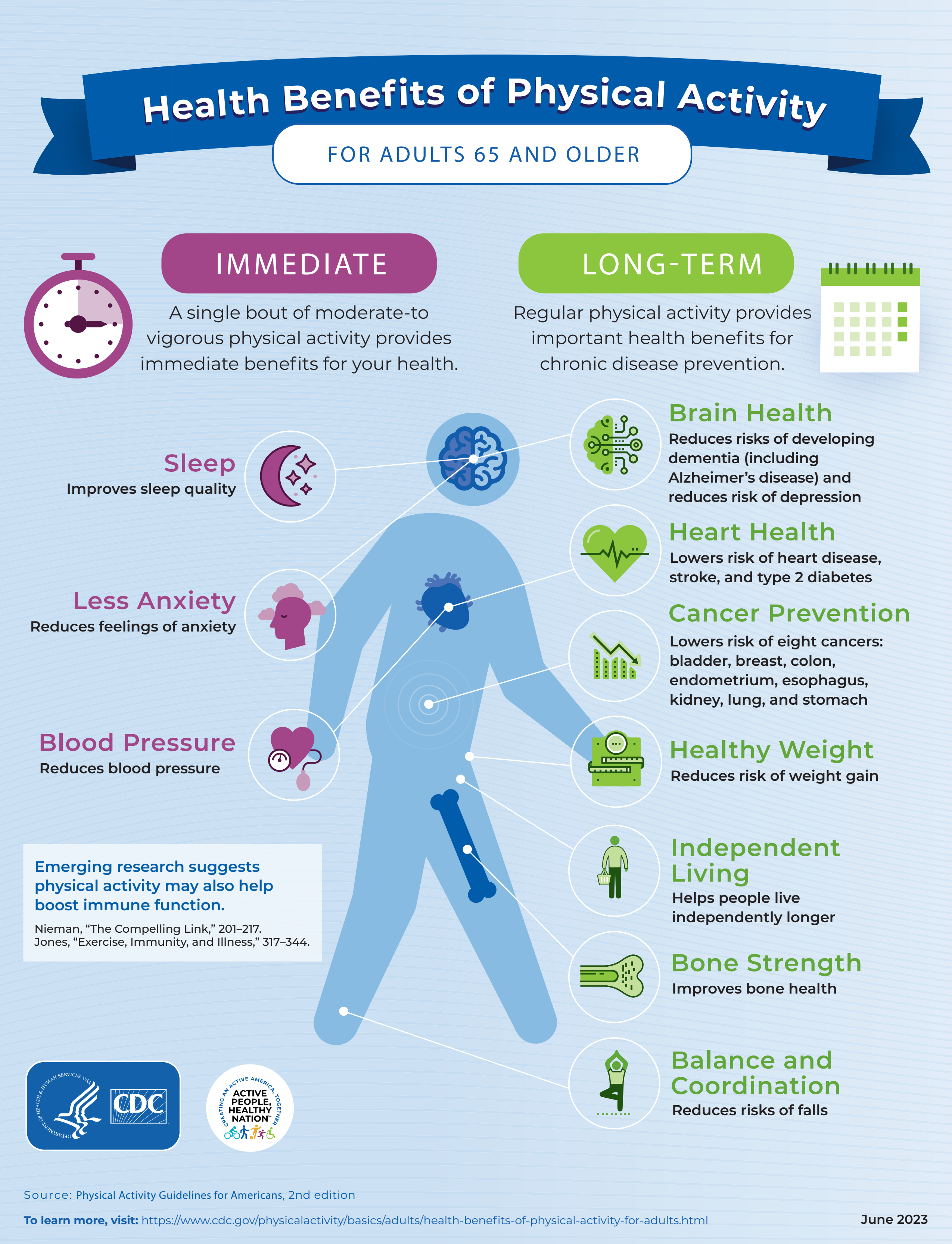
Good feet and ankle mobility makes life more comfortable. It also helps to prevent falls by strengthening small supportive muscles that react to regain balance when we start to sway. Write the full alphabet in the air, once with each food. (It doesn't matter if you write capital or lower case letters.) By the time you finish writing the letter Z, you will have moved your ankles and feet in lots of different directions.

- *How to do it*: Sit in a sturdy chair, and rest your palms on your thighs. Tighten your stomach muscles, and lift one foot a few inches from the ground. Imagine the letter A and use your toe to write it in the air. Repeat with the letter B and so on.
- *Make it easier*: If you ankles are stiff, make the alphabet movements smaller so that you stay within a comfortable range of motion.
- *Make it harder*: If you are able to comfortably write larger letters, go for it! You may also want to challenge your balance by standing on one foot and writing with your lifted leg. Just be certain to have something sturdy nearby to hold onto if you need support.

Seated Leg Extensions

Improving knee strength makes walking and standing more comfortable. This exercise is particularly good at targeting the muscles in the front of the leg. Try doing 10 leg extensions with your right leg, then switch to your left leg.

- *How to do it*: Sit in a sturdy chair with feet flat on the floor and palms resting gently on your thighs. Begin to slowly straighten one leg. Pause, then slowly bend the knee moving the foot back to the floor.
- *Make it easier*: Sometimes it can be uncomfortable to straighten the leg all the way. If this movement bothers your knee, try extending the leg, but stop just before you feel discomfort. It shouldn't hurt!
- *Make it harder*: If you have a friend with you, ask him



Health Benefits of Physical Activity

FOR ADULTS 65 AND OLDER

IMMEDIATE

A single bout of moderate-to vigorous physical activity provides immediate benefits for your health.

LONG-TERM

Regular physical activity provides important health benefits for chronic disease prevention.

Sleep

Improves sleep quality

Less Anxiety

Reduces feelings of anxiety

Blood Pressure

Reduces blood pressure

Emerging research suggests physical activity may also help boost immune function.

Nieman, "The Compelling Link," 201–217.
Jones, "Exercise, Immunity, and Illness," 317–344.

Brain Health

Reduces risks of developing dementia (including Alzheimer's disease) and reduces risk of depression

Heart Health

Lowers risk of heart disease, stroke, and type 2 diabetes

Cancer Prevention

Lowers risk of eight cancers: bladder, breast, colon, endometrium, esophagus, kidney, lung, and stomach

Healthy Weight

Reduces risk of weight gain

Independent Living

Helps people live independently longer

Bone Strength

Improves bone health

Balance and Coordination

Reduces risks of falls

Source: *Physical Activity Guidelines for Americans*, 2nd edition

To learn more, visit: https://www.cdc.gov/physicalactivity/basics/adults/health-benefits-of-physical-activity-for-adults.html

June 2023

Centers for Disease Control and Prevention. Physical Activity Benefits for Adults 65 or Older, Dec. 4, 2025. Accessed at www.cdc.gov/physical-activity-basics/health-benefits/older-adults.html.

or her to place their hands on your lower shins and apply just a little bit of resistance there as you lift. The resistance should be light enough that you can extend your leg, but hard enough that you feel an additional challenge.

- *When to stop*: If you've had a knee injury in the past, check with your doctor or physical therapist to make sure this exercise is safe for your body.

Sit to Stand

This exercise strengthens the front and back of your legs, as well as your glutes. Start with three to five repetitions and progress up to 10 repetitions.

- *How to do it*: Sit comfortably in a sturdy chair with your feet on the floor. Slowly stand up. Once standing, pause, then slowly return to a seated position. The pause is important because it helps your body and mind to settle. Slow movement is also important because it helps to build strength.
- *Make it easier*: Use the arms of the chair to assist you as you stand. If you don't have an arm chair, move your chair in front of a secure countertop and use the surface to assist you by placing your hands on it as you push.
- *Make it harder*: Try to stand without using your arms to push. Once you are able to stand easily without your hands, challenge your balance by standing with one eye closed, or maybe even both!
- *When to stop*: If you have pain in your knees or hips, or if your legs are too weak to stand even when pushing with your arms, check with your doctor or trainer.

Arm Push

Arm pushes work many muscles at once. Your arms, shoulders, upper back, chest and even your abdominal muscles will all benefit! Try three to five arm pushes to start with, and work your way up to 10.

- *How to do it*: Stand facing a wall without furniture in front on a non-slip floor surface. Extend your arms and place your palms flat on the wall at shoulder height. Your feet and hips should be under your shoulders to start. Stand tall and tighten your stomach muscles. Bend your elbows and allow your upper body to slowly move toward the wall. Feel the resistance in your arms as you prevent your upper body from moving too quickly, and stop the movement before your nose touches the wall. Pause, then slowly push your palms against the wall, allowing your arms to straighten.
- *Make it easier*: The closer your feet are to the wall, the easier the arm push will feel. Of course, in this exercise, your feet can't be any closer to the wall than the length of your arms. If it is too difficult to lean all the way to the wall or to push away, just do what you can, bending your elbows less so that your upper body has less space to travel.
- *Make it harder*: The farther your feet are from the wall, the harder the arm push will feel. Try moving your feet farther behind you (just by a few inches), place your hands on the wall and try again until you find just the right distance for you to complete five repetitions. When five repetitions becomes too easy, try 10.
- *When to stop*: If you feel discomfort in your shoulders or wrists, even after modifying the exercise to make it easier, check with your doctor or trainer.

Stretching

Stretching feels good and keeps you limber. Your stretches should feel comfortable, so don't strain. Hold each stretch for about 30 seconds to one minute.

- *Cow stretch*: The cow is a multi-muscle stretch that is perfect for the back of your legs, your lower and upper back and your shoulders and upper arms. Place your hands on the back of a counter top or a sturdy chair without wheels. Feet should be shoulder-width apart. Take a few steps back so your arms are straight. Then, bend forward at the hips, round your back just a bit and enjoy that feeling of elongating your spine. *Ah!*
- *Goal post arms with staggered stance*: Goal post arms are a nice stretch for the front of your shoulders. By staggering your legs, putting one in front of the other, you'll also feel a stretch in the front of your hips and thighs. Stand next to a door frame, lift your arm and bend your elbow so that each is at 90 degrees. Your legs are hip width apart with one foot a few feet in front of the other. Tip your hips forward and feel the stretch in the back of your thigh as you feel a stretch in the front of your shoulder. Don't forget to turn around and stretch the other side.

Consistency Counts

Staying active may not require fancy equipment, but it does take consistency. Find activities that not only feel good but that are also beneficial. Then start slow and adjust as you go. Staying active can add years to your life, and life to your years!

AMY SCANLIN, MS, is a freelance writer and editor specializing in medical and fitness topics.

Diagnosing and Treating Good's Syndrome

While difficult to diagnose, this ultra-rare condition is well-managed with surgery and ongoing immune support.

By Jim Trageser

IN 1954, Robert Good, MD, PhD, wrote a paper for the *Bulletin of the University of Minnesota Medical School* describing a patient who had both a type of thymus cancer and an unusual immunodeficiency, leading to frequent infections. This combination of conditions is now known as Good's syndrome (GS) — although the specific relationship between the cancerous growth and the lack of immune cells remains unclear.[1]

It is not only among the rarest of immune deficiencies, but is also one of the rarest of all medical conditions, with fewer than 400 cases ever reported, and it only develops in middle age and later — between the ages of 40 and 70 years.[2] (Researchers caution that in poorer nations, most if not all cases may go undiagnosed and thus unreported.) Adding to the mystery of the disease is the fact that most patients are in good health up to the point of diagnosis.[3]

There is no single test to diagnose GS, and its cause remains unknown. There is also no cure, although for many patients it can be successfully managed. Treatment generally includes removal of the tumor and tackling any current infections, as well as assisting the immune system in warding off future infections.

But with so few cases, researchers admit there are far more questions about GS than answers.

What Is GS?

GS is the presence of both a thymoma — a type of cancer of the thymus gland — and hypogammaglobulinemia, which is a condition marked by low levels of antibodies in the bloodstream.

The thymus (a gland located between the lungs behind the sternum) is a key part of the immune system, being a sort of training ground for T cells when people are young. But while the thymus is critically important from before people are born up through puberty, in early adulthood it begins to shrink and is replaced by fat cells. By the time GS manifests in late adulthood, the thymus plays little to no role in regulating the immune system.[4]

There is some disagreement in the medical community about how to classify GS. In 2005, an article in the *Annals of Allergy, Asthma & Immunology* classified GS as a subtype of common variable immunodeficiency (CVID).[5] However, in 2012 both the World Health Organization and the International Union of Immunological Societies listed it as a distinct condition — although minus the usual definition of a diagnosis.[1] Further, GS is generally marked by a decreased number of B cells, which is not normally found in CVID. And, CVID almost always manifests before the age of 40. One suggestion has been to define a new diagnosis of "immunodeficiency with thymoma,"[1] which is how the admittedly nonauthoritative Wikipedia lists it (the editors there actually flipped the description, to "thymoma with immunodeficiency").

Of course, part of the difficulty doctors and researchers face in trying to get a handle on this condition is the fact that it is so incredibly rare. With fewer than 400 cases total to study, scientists have very little data with which to work.

Only about one out of every three million people develop GS in their lifetime. In fact, only about 400 cases of thymus cancer occur in the United States each year,[6] and 10 percent of those cases are carcinomas that are not associated with GS. Of the roughly 360 cases of thymoma in the United States each year, only a handful will develop a serious immune deficiency along with the cancer, with similar rates seen in Europe.

What Causes GS?

The underlying causes of GS are unknown, as are the specific triggers that lead to its development in mature adults. However, thymoma is thought to be associated with mutations on four specific genes: GTF2l, HRAS, NRAS and TP53.[2]

Anemia is a frequent side effect, and this has led to one recent paper suggesting — although the authors admit it is not yet proven — that the cancer may be causing the anemia.[7] The authors of this paper also indicate that most researchers now believe GS is not a genetic condition. They also argue that some other genetic mutations found in two GS patients do not indicate the genes themselves cause GS nor even increase susceptibility to it; we simply do not yet know enough.

> **Due to the rarity of GS, there is no accepted standard of care; treatment is tailored to each patient's specific needs.**

How Is GS Diagnosed?

Without a standalone test, nor even an accepted diagnostic standard, GS is diagnosed by a doctor based on the presence of thymoma and an immunodeficiency consistent with GS.

The thymoma is generally detected when a patient reports a persistent cough, shortness of breath, difficulty swallowing or swelling of the face or neck. Other symptoms may include muscle weakness and drooping eyelids from myasthenia gravis, or fatigue due to pure red cell aplasia, all caused by or associated with the thymoma.[8]

An X-ray, MRI or other imaging scan will confirm the presence of the tumor on the thymus, although a biopsy will be necessary to determine for certain that the tumor is a thymoma and not a carcinoma. The two types of tumors generally have distinctive shapes that can be ascertained during imaging, but an examination of cells under a microscope is the only way to know for sure.[9] (A thymoma is a slow-growing, often localized tumor, while a thymic carcinoma is a very aggressive cancer — and is not associated with GS.)

In addition to confirming the presence of a thymoma, a doctor will test for an immunodeficiency — specifically looking for the absence of B cells, low levels of CD4 T cells and lower than normal levels of T-cell mitogen proliferation (the protein that triggers T cells to begin dividing during an infection).[8] This pattern differs from other forms of immunodeficiency and helps doctors narrow in on a diagnosis of GS.

How Is GS Treated?

Due to the rarity of GS, there is no accepted standard of care. Each physician — or, more realistically, each team of physicians — tailors treatment to the specific symptoms of the patient. The care team typically consists of an oncologist and immunologist working together to come up with an effective plan.

Treatment generally begins by focusing on the cancer and addressing any ongoing infections — whether bacterial, viral or fungal. Because there is no cure and GS is chronic, ongoing treatment will likely include intravenous immune globulin (IVIG) to assist the body in fighting future infections.

Interestingly, removing the tumor does not affect the immunodeficiency.[10] But it does remove a significant source of stress on the body.

Recent advances in video-assisted and robotic surgical techniques, particularly in the upper chest cavity, have reduced the need to cut through the breastplate — resulting in reduced odds of contracting a post-operative infection at the incision site.[11] In addition, video- and robotic-assisted procedures increase the chance of removing the entire malignancy when compared to traditional surgery. Finally, robotic thymectomy results in a shorter postoperative recovery period, lowering the risk of pneumonia[12] and other healthcare-acquired infections.

Since many, if not most, cases of GS are diagnosed due to a patient suffering repeated infections, addressing any ongoing infections is the second prong of treatment. Patients with GS are particularly prone to opportunistic infection, and are susceptible to attack by virus, bacteria, fungi and other parasitic organisms that can easily bypass a weakened immune system. Depending on the type of infection a patient contracts, antibiotics are prescribed for that specific infectious agent. (A recent survey of clinical reports on GS patients found that of 152 patients, all but 24 presented with an active infection. Bacterial infections ranged from strep and staph to salmonella and Clostridium difficile. But other patients had fungal and even parasitic infections, including Toxoplasma gondii and Babesia microtii.[1])

The third prong of treating GS is to strengthen the patient's immune system. While, again, there is no formal, accepted course of treatment for GS due to its rarity, most articles regarding GS treatment indicate the physicians prescribed IVIG to help restore immunological function.

Taking a look at several recent articles in medical journals illustrates just how widely treatments may vary from patient to patient.

One article from the June 2024 issue of *Clinical Case Reports* looked at a 63-year-old male originally treated for long COVID.[13] After he was readmitted to the hospital several times for recurring symptoms, doctors recommended additional testing — which the patient declined. After more than two years of ongoing symptoms of COVID, a CT scan detected a thymoma.

Blood tests indicated a compromised immune system, and he also exhibited skin lesions consistent with lichen planus, a rare side effect of GS. The patient was put on IVIG, along with steroids, which combined to improve his condition to where he could be discharged. However, he was readmitted several months later with sepsis due to an E. coli infection, as well as a throat infection of Klebsiella bacteria. He was prescribed colistin to treat the throat infection and meropenem for the E. coli.

Another case, described in a 2015 article in *The Annals of Thoracic Surgery*,[14] involved a 58-year-old male who sought care when a skin lesion wouldn't heal. He also had a persistent cough, and was found to have a large thymoma. A marrow biopsy confirmed the absence of B cells, and a blood test was negative for HIV, leading to a diagnosis of GS. When removed, the thymic tumor was found to weigh more than two pounds. Following surgery, the patient was put on IVIG and filgrastim to boost his immune system. Some 10 months after the surgery, he returned to his physician with salmonella diarrhea. He was put back on IVIG and filgrastim, and he responded positively.

Looking Ahead

While one has a much greater chance of being struck by lightning than of developing GS, it's obviously fairly easy to avoid lightning. With no known cause for GS, and thus no way of preventing it, at this point it appears as largely a matter of fortune as to who develops it and who does not.

Seeking prompt treatment for repeated infections, or for any of the symptoms of a thymoma, is key to obtaining a prompt diagnosis and starting treatment as soon as possible. And unlike the patient described in *Clinical Care Reports*, when offered the opportunity for further testing, we all want to make sure we take advantage of those opportunities.

As with all medical conditions, when it comes to GS, knowledge is power.

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Produced by IG Living magazine, written for patients treated with immune globulin therapy and their caregivers

Profile: Bryan Jirsa

AN ATHLETE at heart, Bryan Jirsa played recreational sports throughout elementary and middle school and went on to compete on his high school football, wrestling and baseball teams. At the same time, he lived with constant, often unexplained illness. Sinus infections, ear infections and sore throats were a regular part of life — so common that his family largely accepted them as normal. As an infant, Bryan required tube feeding until the age of 3 and received immune globulin (IG) infusions for a suspected immune problem, though no clear diagnosis followed.

By Trudie Mitschang

It wasn't until Bryan was 15 years old that doctors were finally able to name what had shaped his health from the beginning: common variable immune deficiency (CVID). Today, after overcoming multiple health crises, including kidney failure and a transplant, Bryan uses his experience to mentor others and inspire resilience. His journey is one of perseverance, purpose and hope.

Trudie: What was it like growing up with chronic illness before you had your diagnosis?

Bryan: Growing up, being sick was just part of my normal. I constantly had sinus infections, ear infections and sore throats, and because it had always been that way, we didn't really question it. As a baby, I needed tube feeding until I was 3 years old and received IG therapy for a suspected immune issue, but there were still so many unknowns.

Even with all of that, I played sports and tried to live like other kids my age. I didn't want to feel different, and for the most part, I didn't let myself think about it too much. Illness was always there in the background, but it wasn't something I had language for yet.

Trudie: When did things start to shift toward finding a reason for your symptoms?

Bryan: In eighth grade, I got swine flu, and that really changed things. It led to extensive immunologic testing and a much deeper investigation into what was going on with my immune system. The process took nearly two years, but when I was 15, I was finally diagnosed with CVID. Having a diagnosis brought answers, but it also opened the door to a lot of fear and uncertainty.

Trudie: How did you process that diagnosis as a teenager?

Bryan: Honestly, it was incredibly hard. I remember the night my parents sat me down after we got the letter from the immunologist. I nodded along and acted like I understood what it all meant, but inside I was completely overwhelmed. I didn't yet have the emotional tools to process something so heavy. Not long after, I started having nightmares about getting sick and dying. That fear sat with me quietly, but it was always there. At that age, you're just starting to imagine your future, and suddenly everything feels fragile.

Trudie: At some point, your mindset shifted. What changed?

Bryan: I realized that I had a choice in how I was going to live with this. I asked myself, "Is this something I'm going to dread every single week during infusions, or is it something I can make the best of and maybe even use to help others?" Once I reframed it that way, everything changed. I began to see my diagnosis not as a limitation, but as something that could give me perspective and purpose. I started looking at life with an expectation of possibility rather than restriction.

Trudie: Community seems to have played a big role in that shift. Can you talk about your experience with the Immune Deficiency Foundation (IDF) Teen Escapes?

Bryan: Teen Escapes completely changed my life. For the first time, I was surrounded by people who truly understood what living with a primary immunodeficiency is like — no explanations required. We shared experiences, fears and victories in a way I'd never had before. Many of the relationships I formed through Teen Escapes are more than a decade old now. They're my second family. Those connections helped me feel seen, understood and supported during some of my most formative years.

Bryan was diagnosed with CVID as a teenager, even after having suffered infections throughout his childhood. Today, he's an elementary school physical education teacher and serves as a mentor for the Immune Deficiency Foundation's panels and Teen Escapes, helping both teens and their parents understand how to live and cope with a primary immunodeficiency. Shown here is a Halloween party at the school where he teaches.

Trudie: You've also spent years mentoring other young people with primary immunodeficiency. What impact has that had on you?

Bryan: Speaking on panels at IDF conferences and Teen Escapes taught me so much about leadership and empathy. Many kids talked about how their parents were afraid to let them do things because of infection risks, and I understand that fear. We encouraged them to stretch beyond their comfort zones while still making smart health decisions. Seeing kids gain confidence and independence was incredibly meaningful. I believe it's important to be a role model and a confidant for younger people who are struggling. I learned the importance of mental health much later in life, and if I can give someone hope sooner than I had it, that means everything to me.

Trudie: You also speak directly to parents, which is incredibly powerful.

Bryan: That's something I care deeply about. I was a failure-to-thrive baby, and now I live a full and meaningful life. A diagnosis like CVID is overwhelming, but it doesn't mean the end of joy or purpose. I want parents to see the long view — to understand that while the road may be hard, there is still so much possibility ahead for their children.

Trudie: Today, you're an elementary school physical education teacher. How do you use your experience to inspire your students?

Bryan: I try to teach my students that challenges don't define what's possible for them. Whether it's a physical limitation or something else they're dealing with, I want them to know it doesn't have to stop them from trying. I focus on effort, resilience and adaptability. I want them to learn early that setbacks don't mean failure — they're just part of the process.

Trudie: In adulthood, your health journey took another turn with kidney disease. Can you share what happened?

Bryan: In 2016, I developed kidney disease caused by CVID. I didn't realize autoimmune complications were even possible, but my body began attacking my kidneys, leading to focal segmental glomerulosclerosis. I tried medications for years, but my condition continued to worsen. At one point, doctors intervened to prevent a stroke due to extremely high blood pressure. That's when we began searching for a kidney donor. My mom, dad and girlfriend all started the evaluation process. Eventually, kidney failure required dialysis three times a week. I'd start three-hour treatments at 6 a.m. and then go straight to work teaching. That period was incredibly difficult. It was the first time I truly experienced depression, along with frequent hospital stays and a lot of uncertainty about the future.

Trudie: How did you get through that difficult time?

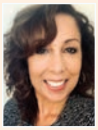
Bryan: I try to maintain a positive mindset even when things look bleak, but I've learned that positivity doesn't mean ignoring your emotions. I had to allow myself to feel everything — fear, sadness, frustration — to process it. Letting myself experience those emotions helped me move through them instead of staying stuck.

Trudie: When were you approved for a kidney transplant?

Bryan: My mom was approved as a donor in January 2023, and she turned out to be a perfect match. When the transplant happened in March, the kidney worked immediately. When I look back, I realize she gave me life twice — once at birth and once through the transplant. That level of gratitude is something I'll never fully be able to put into words.

Trudie: What advice do you have for young people living with chronic illness?

Bryan: My biggest piece of advice is to let yourself feel your emotions as they come. A lot of young people push their feelings down when it comes to their diagnosis, and I did that for years. I've had to unlearn unhealthy coping habits and ways of processing disappointment. I wish I had known earlier that it's OK to experience all of your emotions — even the intense ones — and to recognize you're not alone. When you allow yourself to do that, you can develop healthier coping skills and truly learn how to live life to the fullest.



TRUDIE MITSCHANG is a contributing writer for *IG Living* magazine.

Navigating the Dating Game with a Chronic Illness

By Whitney L. Ward

DATING IN this day and age is hard. Add a chronic illness to that, and it can seem hopeless. The moment you begin to talk to someone who could potentially be your girlfriend or boyfriend, the initial excitement you have at the beginning of the relationship often contrasts with the stark dread of "when, how and do."

When do I tell them I have a chronic illness? *How* can I tell them without scaring them away? *Do* I talk about the daily things I have to do to manage my illness? Because the daily routine I perform on autopilot may be too overwhelming for that person.

I've faced this many times when it comes to dating. I start getting to know a person, and we get to the point I know the time has come. I need to tell him about my immune deficiency. Sadly, many times the budding relationship ends after that.

But in August, I met someone who showed me there are single people in the world who are still looking for the qualities in a relationship that have substance: trust, respect, love, intention and a genuine effort to show someone you care. And after having been in a relationship for these past five months, I have learned so much, so I want to share.

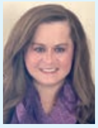
1) *Sharing is caring.* The most common question people with a chronic illness have is, "When is it the right time to share my health struggles with my possible partner?" When I met the person I'm dating now, I knew I didn't want to spend two to three months getting to know him and then see him disappear after I told him about my chronic illness. I was exhausted from the roller coaster of "maybes" that turned into "nos."

So, a few days after I met him, I shared my story through a text message. And because I have a website for my speaking engagements and the book I have published, I gave him the link to my website and told him if he wanted to know more, he could visit my website to read my entire story. I'll never forget his response: "Why would this be deal-breaker for me? Communication and respect for each other are all I care about." I was stunned because I had never had a guy say that to me before, but it made my heart feel hope that there are people who focus on the qualities of depth and character, before making assumptions about a person's situation.

2) *Dominance vs. complement.* If your significant other believes he or she is superior in the relationship, that's a red flag. Just because you have health issues doesn't mean you have less to give. If the person you're dating focuses on the right things, he or she will see that people who have chronic illnesses have an amazing ability to adapt in almost every situation. That person will also watch as you persevere through the unknowns of an immune deficiency and become stronger than before. And he or she will admire the fighting spirit you have because every time you fall, you get back up. Dating and marriage are difficult because two different people are becoming one, but the fact that you have a chronic illness and have developed these skills will be an asset to any challenge you might face together.

3) *Caretaker or helpmate?* Make sure your significant other knows you want a helpmate, not a caretaker. You're in the relationship to encourage and lift that person up as much as he or she does for you. Most of us with chronic illnesses have had years of experience managing our vast medical care, and we know what works or doesn't work. Your boyfriend or girlfriend shouldn't see you as helpless or incapable just because you have multiple treatments and medications to take. If your partner begins exhibiting a condescending attitude toward you, trying to take charge of the situation, then it is time to reevaluate the relationship. You're the expert on what you need. If your significant other cares about you, he or she will ask how to help and assist you when you tell him or her what you need — not what he or she *thinks* you need or *should* be doing. I have had two experiences that have shown me the difference. One of the men I dated told me I should use my illness to get out of doing things I didn't want to do. The guy I'm dating now has told me one of the reasons he's attracted to me is because of my outlook on life despite all I have been through. The latter is what a helpmate looks like.

The bottom line is this: It's your voice, your story and your truth. When and how you choose to handle the painful world dating can be, remember that when it comes to your chronic illness, it's you who calls the shots.



WHITNEY L. WARD was not only the first person in the world diagnosed with MAGIS syndrome, but she also had the honor of naming the new primary immune deficiency. MAGIS means "more" in Latin, and Whitney hopes to instill in her readers the message they are more than their disease. Find out more about Whitney's journey at www.whitneylaneward.com.

When Everything Is New Again: Trusting the In-Between

By Michelle Searle

YOUR 20S are exciting, full of opportunity, freedom and possibility. But what we don't talk about enough is how destabilizing they can be. How often everything changes at once. Where you live, what you do for work, who you're surrounded by and how grounded you feel in your own body. This decade is defined by transition and uncertainties. Jobs begin and end. Cities come and go. Relationships shift. Plans change quickly, sometimes before you've even had time to adjust to the last shift in your life. It's thrilling and overwhelming in equal measure. Even when the change is chosen and it's something you want, it still costs something.

I'm in one of those seasons again right now. It's currently January as I write this from Florida, and I just finished my job in Portugal where I lived for the past four months. I've spent weeks searching for a new job and just received an offer letter for a dream job. I'm moving back to Italy next week because my husband got a job in Milan. So I'm once again navigating moving to a new city, starting a new job, establishing a new healthcare team, etc. I'm also navigating the reality of losing my health insurance and figuring out what coverage will look like moving forward in the U.S. On paper, these are very exciting steps. In real life, they're layered, complicated, thrilling and exhausting.

Recently, I've been realizing that change doesn't just affect our plans, it affects our bodies. During periods of transition, I notice it physically. I expect adjustment to be seamless, as if my mind and body should instantly catch up to my circumstances. But transitions demand energy. They ask us to stay alert, flexible and emotionally available, even if we're craving stability.

Living with a chronic illness adds another layer to this constant motion. When life changes, my healthcare changes with it. Moving means finding new doctors, transferring medical records, learning new systems and starting over — again. I hate having to find new doctors. I hate having my care scattered across different places. Living between countries means never fully belonging to one system, never feeling completely backed by a team that knows you well. There's something very unsettling about being in between places without that safety net. Even if everything is technically handled, it's hard to shake the feeling that you're on your own. That kind of uncertainty lives in the body, not just the mind. It shows up as tension, fatigue and a low-level anxiety that can be easy to dismiss, but impossible to ignore.

And still, this is what your 20s are often like. Constant movement. Constant reinvention. We don't give this decade enough credit for how much it asks of us. We're expected to be adaptable, resilient and grateful all at once, without acknowledging the toll of always changing or starting over. I know I don't give myself enough grace in these moments. I move from one transition to the next without pausing to acknowledge how challenging it is. Adjusting isn't something you rush through or ignore. It's something you flow with.

These seasons are temporary. One day, many of us will be settled. We'll live in the same city for years. We'll have established careers, familiar routines and a consistent circle of people. Life will feel steadier. And when that happens, I think many of us will look back on this period of chaos, uncertainty and constant change with nostalgia and fondness, not because it was easy, but because we felt alive.

These years shape us in ways we won't fully understand until later. They teach us how to tolerate discomfort, how to advocate for ourselves and how to keep moving forward without guarantees. They force us to build resilience that comes from navigating uncertainty and learning to trust yourself. Embracing change means acknowledging how it affects you mentally, physically, emotionally. It means allowing yourself to grieve what's ending if that's what you feel, while still excited to step into what's next.

At the same time, I don't want to lose sight of how fun this decade is. There's something exciting about being in a season of life where flexibility still exists, where you can change cities, try a new job or say yes to something unexpected. I'm grateful to be in a position where this kind of movement is possible. Not everyone gets this freedom, and I don't take it for granted. My 20s have been full of opportunity, growth and stories I know I'll always carry with me.

MICHELLE SEARLE is a teacher from South Florida who was diagnosed with common variable immunodeficiency at 11 years old. She is currently living in New York where you will most likely find her eating pizza or trying to make friends with the local cats.

Nutritional Deficiencies in Kids with PI

By Jessica Leigh Johnson

PARENTS OF children with primary immunodeficiency (PI) are very familiar with looking out for signs of infections such as a cough, fever or drainage from the nose that is not clear in color. These signs mean a trip to the doctor or another round of antibiotics may be necessary. But there are other physical symptoms that can be experienced by children with PI that point not to infection, but to a nutritional deficiency, and parents need to be aware of this possibility and what symptoms to look out for.

Why Proper Nutrition Is Crucial for Kids with PI

Whether a child has PI or not, his or her immune system relies heavily on different nutrients to function properly. For children with PI, whose immune systems are already lacking key components, being deficient in certain vital nutrients can make symptoms worse or recovery from illness slower. When a child suffers from symptoms such as delayed or stunted growth, frequent tummy troubles, low energy or delayed recovery from infections, it might not be solely due to their immune deficiency. A nutritional deficiency may actually be to blame.[1]

The frustrating part is that many kids with PI face challenges that make getting proper nutrition more difficult in the first place. These issues, common in many forms of PI, include:

- Frequent infections that reduce appetite, leading to less-than-adequate nutritional intake
- Chronic diarrhea and/or gut inflammation that leads to nutrient loss
- Increased energy demands due to illness and fevers, depleting nutritional stores

- Side effects of medications that affect appetite and cause stomach upset

Because of these common PI issues, even children who eat a well-balanced diet can still end up with a nutritional deficiency.

The Most Common Nutritional Deficiencies in Children with PI

Not every child with PI will develop a nutritional deficiency, but for those who do, certain deficiencies show up more often than others. Knowing what is most common can help parents and doctors find the right solution.

1) *Vitamin D.* Low levels of vitamin D are common in children with PI, especially those who spend limited time outdoors due to illness or infection risk. This is why children who live in northern climates, where less time is spent exposed to the sun because of cold weather, can have low levels of vitamin D. According to the Immune Deficiency Foundation, "Vitamin D is important in helping phagocyte function, limiting inflammation by T cells and promoting wound healing."[1] Signs of low vitamin D include frequent infections, bone or muscle pain, fatigue and delayed growth. A simple blood test can reveal vitamin D deficiency, and along with diet changes, supplementation can be beneficial.

2) *Iron.* "Iron is a vital component of hemoglobin, which makes it an important mineral that our bodies need in order to carry oxygen so that our cells can produce energy," explains registered dietician Julia Zumpano. "If we don't have enough iron, we will not have enough red blood cells to transport oxygen. This leads to extreme fatigue and lightheadedness."[2] Chronic inflammation, frequent infections and gastrointestinal issues can interfere with iron absorption. Signs of low iron include pale skin, low energy and fatigue, shortness of breath with activity (like climbing stairs), difficulty concentrating and hair loss.[3] If a child has an iron deficiency, it can lead to anemia, which is why frequent monitoring of hemoglobin and ferritin levels is crucial. Iron deficiency can be helped by eating iron-rich foods and taking supplements. Because iron supplements can lead to issues such as constipation and iron poisoning, they should never be given to children without a doctor's supervision.

3) *Zinc.* Zinc aids children in growth, wound healing and immune response. A deficiency in zinc can impair the function of neutrophils, NK cells, T and B cells, and can even compromise the production of antibodies. Even having a slight deficiency in zinc can affect how often children get sick and how fast or how well they recover. Signs of zinc insufficiency can include poor appetite, slow growth, frequent colds and infections (which may not be a noticeable "red flag" in immune-deficient children), skin rashes and

slow-to-heal wounds.[4] A zinc deficiency may be even more common in children who suffer from frequent diarrhea and/or malabsorption.

4) *Vitamin A.* "Vitamin A is particularly important because it supports the structure and function of the mucosal cells of the eyes, lungs and gastrointestinal tract. A lack of vitamin A can impair B and T cell response, cause loss of structure/function of cells on mucosal surfaces leading to impaired resistance to infections (particularly in the gastrointestinal tract), and diminish innate immunity,"[1] says Pediatric Allergist and Immunologist Elizabeth Wisner. Some children with PI struggle with GI issues such as chronic diarrhea, Crohn's-like symptoms and inflammatory bowel symptoms. Children with these issues may fail to absorb fat-soluble vitamins like vitamin A, but also vitamins E and K. Signs of deficiencies in these vitamins are vision problems, easy bruising, dry skin and increased infections. These deficiencies tend to be less obvious and may not be identified by symptoms alone, but rather through blood testing.

Signs Parents Should Look Out For

Some nutritional deficiencies are "silent" and have no symptoms, while others are more obvious. Since parents know their child best, they need to pay attention and trust their gut when something doesn't seem quite right. Look for these red flags:

- Poor weight gain or a plateau in the child's growth
- Chronic fatigue, low stamina, tiring easily
- Frequent stomach pain, diarrhea or constipation
- Thinning hair or brittle nails
- Delayed wound healing, bleeding gums when flossing[3]
- Increased frequency or severity of infections

If any of these signs and symptoms become a pattern, parents should seek advice from the child's doctor and ask for testing to rule out or confirm a nutritional deficiency. Without testing, detecting a nutritional deficiency in a child with PI is difficult since many of these signs and symptoms are already common in PI. For example, frequent infections are one of the hallmarks of PI, so it's difficult to tell when the infections are actually frequent because of a nutritional deficiency. It's also important to note that the relationship between nutritional deficiency and immune function is somewhat cyclical, in that nutritional deficiencies can negatively affect immune function, but also, poor immune function (as in the case of PI) can lead to nutritional deficiencies. This cycle can be frustrating and can make the actual underlying cause difficult to pinpoint.

How Parents Can Support Their Child's Nutrition

While all of this may seem overwhelming to parents, there are actually small, easy steps they can take to make a big difference in their child's nutrition. First, focus on nutrient-dense foods. When a child's appetite is limited due to illness or fatigue, the quality of the food matters more than quantity. Foods such as eggs, nuts, yogurt (if dairy isn't an issue) and smoothies can pack more nutrition into a smaller portion. Vitamin A can be found in leafy green vegetables, sweet potatoes, carrots, liver, egg yolks and butter.[1] Vitamin D can be found naturally through sunlight exposure, and by eating certain fish and drinking orange juice and milk that has been fortified with vitamin D.[1] Sources of iron include lean red meat, poultry, fish, spinach, eggs, tofu, broccoli, prunes and many fortified foods like grains, cereals and pastas.[2]

Aside from food sources, supplements are always an option for treating certain nutritional deficiencies, and many kids with PI take supplements — especially vitamin D and iron. However, these supplements should be taken only after labs have confirmed a deficiency and following a doctor's guidance, as too much can be harmful.

If necessary, ask for a referral to a dietitian, preferably a pediatric dietitian with experience dealing with immunodeficiency. The dietician can create a unique meal plan that works for the child's needs and preferences.

Supporting a child with PI is complex, and nutrition is just one part of the overall picture. Thankfully, nutritional deficiencies are manageable with awareness, monitoring and parental support. By understanding the signs and advocating for evaluation and testing, parents can help their children thrive.

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Choosing Vitamins and Supplements

By Rachel Maier, MS

DOES SHOPPING for vitamins and supplements make you scratch your head? Me too! Trying to make sense of what to take, how to take it and which brand to buy makes it feel like it's more trouble than it's worth. The United States Food and Drug Administration (FDA) estimates there are more than 100,000 different kinds of supplements to choose from — no wonder consumers are confused![1]

Vitamins vs. Supplements — What's the Difference?

Vitamins are supplements, but not all supplements are vitamins. Vitamins are essential organic substances your body needs to maintain normal cell function, growth and development.[2] Supplements are anything taken in addition to a regular diet to provide essential nutrients one doesn't get through food alone, including minerals, probiotics, amino acids, enzymes, antioxidants, botanicals, herbs and, of course, vitamins.[3] Products containing these nutrients help people support or maintain a healthy lifestyle. They come in all sorts of forms: tablets, capsules, liquids, gummies, powders, bars, etc.

Unregulated = Unreliable?

Over-the-counter (OTC) supplements are widely available. They're easy to find, fairly affordable and most claim to be high quality, but not all of them deliver needed nutrients safely and effectively. OTC supplements do not have the same requirements as medications. They are not regulated by FDA, which means FDA does not evaluate products for quality, safety or effectiveness before they hit store shelves. However, FDA does require supplement manufacturers to follow good manufacturing practices, which helps ensure product consistency and transparency.[1]

What to Look For

To get supplements that are safe and effective, opt for medical-grade. They're pure, potent and undergo rigorous third-party testing to ensure high-quality product. While not required by law, third-party testing ensures the supplement contains stated ingredients in the amounts indicated on the label, uses standardized formulations and does not contain contaminants such as heavy metals and undeclared ingredients. Look for logos from USP, NSF International or ConsumerLab, which are third-party certification programs that verify the product contains ingredients it claims to contain. And, choose supplements that are in the most bioavailable form, which the body can easily absorb.

Wild Claims and Red Flags

High-quality supplements can certainly deliver nutrients your body needs and help improve your health, but beware of products claiming to be a quick fix, cure-all, the secret to disease reversal or instant transformation. Red flags such as vague language, fake endorsements and even the promise of proprietary blends should give you pause. (Proprietary blends refer to a company's unique mix of ingredients. While these formulas do include the ingredients they claim to include, the manufacturer does not specify the actual amount of the key ingredients, and therefore, obscure the actual dose.) Dig into all the claims, and make sure they are backed by clinical proof.

Talk to Your Doctor

Many supplements are made of natural ingredients such as whey protein, fish oil and turmeric. While generally considered harmless, supplements containing ingredients that are "safe" are one thing, but safe for *you* to take is another. Ingredients may interact with your prescription medications, so confirm with your doctor that any supplements you want to take do not pose a danger to your body. Once you have their approval, go ahead and add high-quality supplements to your health routine.

References

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2. Medline Plus. Vitamins. Accessed at medlineplus.gov/ency/article/002399.htm.
3. United States Food and Drug Administration. Understanding Dietary Supplements. Accessed at www.fda.gov/media/158337/download?attachment.

RACHEL MAIER, MS, is the associate editor of *IG Living* magazine.

Double-Wood Wellbeing Starter Stack

Practitioner grade supplements from Double Wood Supplements meet the highest quality standards. Customers can combine single-ingredient products together to create customized blends (known as "stacks") to address their unique needs. Products are clear, accessible and reliable. This Wellbeing Starter Stack includes a methylated (or "ready-to-use") multivitamin, magnesium l-threonate for memory support and cognitive function and vitamin D3 and K2 blend for immune support. *$79.95; doublewoodsupplements.com/products/wellbeing-starter-stack*

Grüns Superfood Greens Gummies

These once-a-day snackable gummies deliver a powerful punch of critical vitamins and minerals found in fresh greens. They support the gut with prebiotic fiber; aid nerve function with thiamin and folate; promote immune health with vitamins C, D and zinc; and more. Grüns products are regularly tested for pesticides, heavy metals, microbials and other contaminants.
$52.79; gruns.co/pages/vip?snowball=HONGSON30689&gad_source=1

Shopping Guide for Vitamins and Supplements

Pure Encapsulations O.N.E. Multivitamin

Formulated with more than 25 vitamins, minerals and other essential nutrients, this supplement provides vitamins A, B, C, D and E in highly bioavailable forms for optimal absorption. It also includes CoQ10 to support healthy brain function, cellular health, heart function and eye health.* Comes in a convenient all-in-one capsule-per-day dosing.
$23.20 for 30 capsules; smartq.pureforyou.com/products/39251840991266/o-n-e-multivitamin

Thorne's Skin Health Stack

This combo pack contains Collagen Plus and Biotin, two best-selling products to support the health and vitality of skin, hair and nails. Collagen Plus nourishes hair and nails and supports healthy, hydrated skin.* Biotin offers a high concentration of biotin, a B vitamin that promotes fingernail strength and also supports healthy skin and hair.*
$81; www.thorne.com/products/dp/skin-health-bundle

Ther-Biotic ABx Support

This supplement combines the non-pathogenic yeast Saccharomyces boulardii with three beneficial bacteria for use alongside antimicrobial treatment.* It comes in a convenient 14-day supply, perfect for the duration of an antibiotic course of treatment, or a 30-day supply to ensure consistent support for gut health after antibiotic therapy.
$45.99; us.sfihealth.com/k-abx-abx-supportm

Nordic Naturals Magnesium Glycinate

Magnesium glycinate is a highly absorbable form of magnesium that's easy on the digestion and great for relaxation, stress relief and mood balance.* Certified vegan, non-gmo and purity tested.
$21.99; www.nordic.com/products/magnesium-glycinate/?variant=51088815423672

**Editor's note: These statements have not been evaluated by the U.S. Food and Drug Administration. Products are not intended to diagnose, treat, cure or prevent any disease.*

Ataxia Telangiectasia (A-T)

Websites

- A-T Children's Project: www.atcp.org

Chronic Inflammatory Demyelinating-Polyneuropathy (CIDP)

Websites

- GBS/CIDP Foundation International: www.gbs-cidp.org

Evans Syndrome

Online Peer Support

- Rare Connect Evans Syndrome Community Group: www.rareconnect.org/en/community/evans-syndrome/faqs

Guillain-Barré Syndrome (GBS)

Websites

- GBS/CIDP Foundation International: www.gbs-cidp.org
- The Foundation for Peripheral Neuropathy: www.foundationforpn.com

Online Peer Support

- GBS Support Group: www.gaincharity.org.uk
- GBS/CIDP Foundation International Community Forums: forum.gbs-cidp.org

Immune Thrombocytopenia (ITP)

Websites

- ITP Support Association – UK: www.itpsupport.org.uk
- Platelet Disorder Support Association: www.pdsa.org

Kawasaki Disease

Websites

- American Heart Association: www.heart.org/en/health-topics/kawasaki-disease
- American Academy of Family Physicians: www.aafp.org/afp/2006/1001/p1141.html
- Kawasaki Disease Foundation: www.kdfoundation.org
- KidsHealth: www.kidshealth.org/parent/medical/heart/kawasaki.html

Mitochondrial Disease

Websites

- United Mitochondrial Disease Foundation: www.umdf.org
- MitoAction: www.mitoaction.org

Multifocal Motor Neuropathy (MMN)

Websites

- The Foundation for Peripheral Neuropathy: www.foundationforpn.com

Multiple Sclerosis (MS)

Websites

- Multiple Sclerosis Association of America: www.mymsaa.org
- Multiple Sclerosis Foundation: www.msfocus.org
- National Multiple Sclerosis Society: www.nationalmssociety.org

Online Peer Support

- Friends with MS: www.FriendsWithMS.com
- MSWorld's Chat and Message Board: www.msworld.org
- Overcoming Multiple Sclerosis: www.overcomingms.org/community

Myasthenia Gravis (MG)

Websites and Chat Rooms

- Myasthenia Gravis Foundation of America (MGFA): www.myasthenia.org
- Myasthenia Gravis Association: mgakc.org

Online Peer Support

- Genetic Alliance: www.geneticalliance.org

Myositis

Websites

- The Myositis Association: www.myositis.org
- International Myositis Assessment and Clinical Studies Group: www.niehs.nih.gov/research/resources/imacs/index.cfm

Online Peer Support

- Juvenile Myositis Family Support Network: www.curejm.org/fsn/index.php
- The Cure JM Foundation: www.curejm.org
- Myositis Association Support Group: www.myositis.org/patient-support/support-groups
- Myositis Support Group – UK: www.myositis.org.uk

Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS)

Websites

- PANS/PANDAS UK: www.panspandasuk.org
- PANDAS Network: www.pandasnetwork.org
- PANDAS Physician Network Family Resources: www.pandasppn.org/parent-information
- National Institute of Mental Health: www.nimh.nih.gov/health/publications/pandas/index.shtml

Pemphigus and Pemphigoid

Websites

- The International Pemphigus and Pemphigoid Foundation: www.pemphigus.org

Peripheral Neuropathy (PN)

Websites

- Neuropathy Action Foundation: www.neuropathyaction.org
- Western Neuropathy Association: www.pnhelp.org
- Neuropathy Alliance of Texas: www.neuropathyalliancetx.org
- The Foundation for Peripheral Neuropathy: www.foundationforpn.com

Primary Immune Deficiency Disease (PI)

Websites

- Immune Deficiency Foundation: www.primaryimmune.org
- Jeffrey Modell Foundation: www.info4pi.org
- The National Institute of Child Health and Human Development (NICHD): www.nichd.nih.gov/Pages/index.aspx
- American Academy of Allergy, Asthma & Immunology: www.aaaai.org
- International Patient Organisation for Primary Immunodeficiencies (IPOPI) — UK: www.ipopi.org
- Rainbow Allergy-Immunology: www.uhhospitals.org/rainbow/services/pediatric-allergy-and-immunology

Online Peer Support

- IDF Friends: www.idffriends.com
- Jeffrey Modell Foundation Facebook Page: www.facebook.com/JMFworld
- IDF Peer Support Program: www.primaryimmune.org/idf-peer-support-program

Scleroderma

Websites

- Scleroderma Foundation: www.scleroderma.org
- Scleroderma Research Foundation: www.srfcure.org
- Johns Hopkins Scleroderma Center: www.hopkinsscleroderma.org

Online Peer Support

- Scleroderma Support Forum: www.curezone.com/forums/f.asp?=404

Stiff Person Syndrome (SPS)

Websites

- American Autoimmune Related Diseases Association Inc.: www.aarda.org
- Genetic Alliance: www.geneticalliance.org
- Living with Stiff Person Syndrome (personal account): www.livingwithsps.com
- The Stiff Person Syndrome Research Foundation: stiffperson.org

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